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Betty —

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary
Office of Public Health and Science

8/15/00

Dear Heather,

Enclosed is an almost final draft of the agenda for the Surgeon General's Conference on Children Mental Health. In addition, a list of invitees is attached.

It is moving forward!

Beverly L. Malone, PhD, RN, FAAN
Deputy Assistant Secretary for Health
200 Independence Avenue, SW • Room 716 - G • Washington, DC 20201
Tel: (202) 690-7694 • Fax: (202) 690-6960 • bmalone@osophs.dhhs.gov

U.S. Public Health Service

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary
Office of Public Health and Science

7/24/00

Heather,

Enclosed is an update on the status of the Surgeon General's Conference on Children's Mental Health.

A draft of the invitation list will follow in the next week.

Beverly L. Malone, PhD, RN, FAAN
Deputy Assistant Secretary for Health
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John Weisz, Ph.D. UCLA

Systems of Care: Financing and organizing service systems 15+15+10 min

(Content: Structure of reimbursement systems and impact on access and use of MH services. Public-private partnerships. Key elements in implementing effective services in the community. Consumer perspective.)

Richard Frank, Ph.D., Harvard University (to be confirmed)
Robert Friedman, Ph.D., University of South Florida
Angelique Harris (Youth)

Discussants 30 min

Barbara Huff, Federation of Families (Family Member)
Larke Huang, Ph.D., George Mason University
Phillipa Hambrick, Dallas Independent School District
Michael Dennis, Ph.D., Chestnut Health Systems

5:30 - 6:30 General discussion

September 19, 2000

8:00 – 10:00 Breakout session: Facilitated as before (10 groups, 30 per group)

10:00 – 10:15 BREAK

10:15-12:15 Breakout session: Facilitated as before – wrap up recommendations.

12:15-1:45 LUNCH
Reporters synthesize recommendations from breakout groups

1:45-3:00 Reporters report back to Dr. Satcher.

3:00 – 4:30 General Discussion

4:30 – 5:30 *Final session: Summary of Findings*
Facilitated by Dr. Satcher (?)

Note: 300 invitees from professional associations, family advocacy associations, the scientific community, and industry will attend. The final session will identify areas of consensus and recommendations from attendees for policy reforms to improve identification, recognition, treatment, and service delivery for children with mental disorders, based on the best available evidence. The Surgeon General will issue a national action agenda based on the recommendations that come from this conference and

9/6 Ritalin

Mary Beth Donahoe –
concern ct politicize S.G. conference at NIH
bipartisan/independent nature of S.G.

problem – S.G. – NR appropriate to have Senate candidates
at working scientific conference
– he will talk to Chris Jennings today
wants to express his concern

open issues

(1) closed to press – b/c it's a scientific conference
so open for her speech

Oct 21 (2) deliverables – don't know if they can do
status report – –

Research conference – psychotropic drug of NIMH

~~at end~~ result of conference – Action Plan

Oct 2nd – Research mtg

Patrick Kennedy wanted to attend + speak + S.G. declined

Surgeon General's Conference on Children's Mental Health
Confirmed Invitation List (8/14)

Panel Chairs

Mary Jane England, M.D.	**Washington Business Group on Health**
Spero Manson, Ph.D.	**University of Colorado**
Chris Koyanagi, J.D.	**Bazelon Center for Mental Health Law**

Speakers (ones not bolded have not confirmed)

Maggie Alegria, Ph.D.	**University of Puerto Rico**
Dan Takeuchi, Ph.D.	**Indiana Univeristy**
Dan Offord, M.D.	McMaster University
Kelly Kelleher, M.D.	**Western Psychiatric Institute**
Steven Forness, Ph.D.	**University of California, Los Angeles**
Neal Halfon, M.D.	University of California, Los Angeles (To be confirmed)
John Landsverk, Ph.D.	**University of California, San Diego**
Linda Teplin, Ph.D.	**Northwestern University**
Barbara Friesen, Ph.D.	**Portland State University**
C. Veree Jenkins	**Family Advocate**
Ken Wells, Ph.D.	**RAND-UCLA**
Barbara Burns, Ph.D.	**Duke University**
Tim Lewis, Ph.D.	**University of Missouri**
Thomas Laughren, M.D.	**Federal Drug Administration**
Peter Jensen, M.D.	**Columbia University**
Evelyn Green	**Family Advocate**
John Weisz, Ph.D.	**University of California, Los Angeles**
Richard Frank, Ph.D.	Harvard University (To be confirmed)
Robert Friedman, Ph.D.	**University of South Florida**
Lynn Pedraza	**Family Member**
Angelique Harris	**Youth Speaker**
Senora Simpson, Ph.D.	**Family Member**

Discussants (ones not bolded have not confirmed)

James Comer, M.D.	Yale University
Jane Knitzer, Ed.D.	**Columbia University**
Donna Gore Olsen	**Indiana Parent Information Network, Inc.**
Glorisa Canino, Ph.D.	**University of Puerto Rico**
Laurie Flynn	**NAMI**
Carl Bell, M.D.	**Community Mental Health Council, Chicago**
Vera Pina, MSW	**Milwaukee Wraparound**
Michael Faenza	**National Mental Health Association**
Barbara Huff	**Federation of Families for Children's Mental Health**
Michael Dennis, Ph.D.	**Chestnut Health Systems**
Phillipa Hambrick	**Dallas Independent School District**
Larke Huang, Ph.D.	Georgetown University

Professional Associations/Organizations (73)

Ambulatory Pediatric Assn	**Marge Degnon**	**Exec. Director**
American Academy of Family Physicians	**Lanny R. Copeland, M.D.**	**Chairman of the Board**

American Academy of Pediatrics (2 reps)	Louis Z. Cooper, MD, FAAP, President-elect	
American Academy of Child-Adolescent Psychiatry	Clarice Kestenbaum, M.D.	President
American Assn for Marriage & Family Therapy	John Ambrose	Dir. Legal and Gov't Affairs
American Assn of Community Psychiatrists	Steve Goldfinger	
American Association of Health Plans	John Fontanesi, Ph.D	
American Association of Pastoral Counselors	Roy Woodruff, Ph.D.	Executive Director
American College of Emergency Physicians	Robert Schafermeyer, M.D.	
American Counseling Association	Richard Yep	
American Federation of Teachers	Gregory Humphrey, Assistant to the President	
American Institutes for Research	David Osher, Ph.D.	Pelavin Research Center
American Medical Association	Randolph Smoak, Jr., M.D., President	
American Nurses Association	Mary Foley, M.S., R.N.	President
American Orthopsychiatric Asssociation	Jane Knitzer, Ed.D.	
American Occupational Therapy Assn	Paula Steib	Marian K. Scheinholtz, MS, OTR/L
American Pediatric Society and Society for Pediatric Research	Vicki Kane	
American Psychiatric Association	Allan Tasman, M.D., President / (David Fassler, M.D.)	
American Psychological Association (2 reps)	Ronald Levant, Ph.D.	(APA Recording Secretary)
American Psychological Society	Sarah Brookhart	
American Public Health Association	Elaine Ryan, Director of Government Affairs	
American School Health Association	Susan Wooley	
American Sociological Association	Felicia Levine, Ph.D.	
Anxiety Disorders Assn of America	David Rapoport; Deborah Beidel, Ph.D.	
Assn for the Advancement of Behavior Therapy	David Teisler	
Association for Medical Education and Research in Substance Abuse	Jeffrey Samet, M.D., M.P.H., President	
Association of Black Psychologists	Mawiyah Kambon, Ph.D/ Sam Gordon, Ph.D.	
Assn of Maternal and Child Health Programs	Catherine Hess, MSW, Executive Director	
Assn of Medicaid Directors	Lee Partridge, Director of Health Policy Unit	
Assn of State and Territorial Health Officials	Christa-Marie Singleton, MD, MPH	

Black Psychiatrists of America	Ledrow Justice, M.D.
Council of Juvenile Correctional Administrators	Edward Loughran, Executive Director
Emergency Nurses Association	Benjamin Marrett , President
Gay and Lesbian Medical Association	Maureen O'Leary
Int'l Soc of Psychiatric Mental Health Nurses	Linda Finke, Ph.D.
Institute for Family-Centered Care	Beverly Johnson, President
Institute for Child Health Policy	Steve Freedman, Ph.D., Executive Director
Juvenile Law Center	Robert Schwartz, J.D., Executive Director
National Assembly on School-Based Health Care	John Schlitt, Executive Director
National Association for Rural Mental Health	Luanne Rice, President
National Association of Alcoholism and Drug Abuse Counselors	Mark Gallagher, President
National Assn of Psychiatric Treatment Centers for Children	Joy Midman
Natl Assn of Psychiatric Health Systems	Mark Covall, M.D.
National Association of Public Child Welfare Administrators	Ramona L. Foley, President
National Assn of School Nurses	Jane Tustin, RN, MSN, CSN President
National Assn of School Psychologists	Kevin P. Dwyer, M.A., NCSP
Natl Assn of Social Workers	Paula Armbruster, M.A ., M.S.W.
National Assn. of State Mental Health Prog. Directors (2 reps)	Robert Glover, M.D. (Meredith Alden, M.D.,Ph.D.)
Natl Cntr for Educational Disability & Juvenile Justice	Peter Leone
National Child Abuse Coalition	Thomas L. Birch, J.D. Legislative Counsel
National Alliance for Hispanic Health	Jane Delgado, Ph.D.
National Conference of State Legislatures	Mary Fairchild
National Council of Juvenile and Family Court Judges	Judge Ernestine S. Gray
National Depressive and Manic Depressive Assn	Lydia Lewis
National Education Association	Diane Shust
National Families in Action	Sue Rusche, Executive Director
National GAINS Center	Joseph J. Cocozza, Ph.D., Director

National Governors' Association	Nolan Jones, Director, Human Resources Group
National Head Start Association	Sarah Greene, CEO
National Indian Child Welfare Association	Terry Cross, Executive Director
National Mental Health Association	Michael Faenza, MSW President and CEO
National Medical Association	Jackie Threadgill
Nat'l Technical Assistance Center for Children's Mental Health	Sybil Goldman
Pan-american Health Organization	Claudio Miranda, M.D.
Society for Adolescent Medicine	Trina Anglin, M.D.
School Social Work Association of America	Randy Fisher President
Society for Developmental & Behavioral Pediatrics	Debbie Anagnostelis, Executive Director
Society for Prevention Research	Shep Kellam, President
YMCA of the USA	Eden Durbin
Youth Law Center	Mark Soler, J.D., President
ZERO TO THREE	Matthew Melmed, Executive Director

Advocacy Groups/Foundations/Media

Advocates for Youth	Kent Klindera
A.E. Casey Foundation	Mareasa R. Isaacs, Ph.D.
Children's Defense Fund	MaryLee Allen Director
Child Health Foundation	Eric Marler, M.D., Chairman, Execute Committee
Child Welfare League	Shay Bilchik, Executive Director
The Commonwealth Fund	Kathryn Taaffe McLearn
Council for Exceptional Children	Nancy Safer, Executive Director
Council for Children with Behavior Disorders	Reese Peterson, Ph.D., President
Cure Autism Now Foundation	Dr. Carol Sprouse
Casey Family Program	Eileen O'Brien, Ph.D. Office on Early Childhood/SAMHSA
Child & Adolescent Bipolar Foundation	Marjorie Kitzes Vice President
CHADD	Beth Kaplnek, R.N. President Elect
The Carter Center	Gregory Fricchione, M.D.
Carnegie Corporation of New York	Michael Levine, Ph.D., Deputy Chair & Senior Program Officer
The Dana Alliance for Brain Initiatives	David Mahoney
Ewing Marion Kauffman Foundation	Lisa Klein
Family Process	Carol Anderson, MSW, Ph.D
Family Voices (Maryland/DC)	Gail Johnson
Fed of Families for Children's Mental Health	Gail Daniels
Grantsmakers for Children, Youth & Families	Marsha Renwanz, Ph.D.
The John D. & Catherine T. MacArthur Foundation	Laurie Garduque
National Alliance for the Mentally Ill	Laurie M. Flynn
National Campaign Against Youth Violence	Sarah Ingersoll
National Center on Institutions and Alternatives	Lindsay M. Hayes, Assistant Director
National Parent-Teacher Association	Robin Marion
Natl Foundation for Depressive Illness, Inc.	Amy Russell
Obsessive-Compulsive Foundation	Patricia Perkins-Doyle
Oregon Social Learning Center	John B. Reid, Ph.D., Executive Director

Packard Foundation	Ann Segal
Reader's Digest	Claudia Edwards, Executive Director
Research!America	Mary Woolley/ Ray Merenstein,/Matthew Bowdy
Robert Wood Johnson Foundation	Ruby Hearn, Ph.D.
Save the Children	Neil Boothby, Ph.D.
Sister Witness International	Laura Prescott, Executive Director
Suicide Prevention Advocacy Network	Gerald H. WeyraUniversity of California,h
Tourette Syndrome Association, Inc.	Judit Ungar, CSW.
Task Force for Child Survival & Development	Mark Rosenberg, M.D., MPH
W.K. Kellogg Foundation	Gail McClure, Ph.D.
World Federation on Mental Health	Barbara Long
W.T Grant Foundation	Karen Hein, President
UNICEF	(Rolando)

Insurance/Financing/Managed Care/Business Community

American Managed Behavioral Healthcare Association	Pamela Greenberg, M.P.P., Executive Director
The California Endowment	Gwen Foster
Cigna Behavioral Health	David Whitehouse, Senior Vice President
Committee on Government Relations and Insurance	Robert L. Pyles, M.D.
Federal Express Corporation	Bonnie McKeever
Magellan Behavioral Health Public Solutions Group	Danna Mausch
National Institute for Health Care Management Research and Education Foundation	Linda Kotis
Texas Instruments Incorporated	Susan N. Nelson
Texas Integrated Funding Initiative	DeAnn Lechtenberger, Ph.D.
United Behavioral Health	Leon Wanerman, M.D., Vice President and Deputy Medical Director Employer Division
United Behavioral Health	David Nace, M.D.
Verizon	James Astuto, Regional Manager Healthcare
Vida Health Communications	Ms. Lisa McElaney
Washington Business Group on Health	Kristen Apgar, Director

Scientists

Brandeis University	Jack P. Shonkoff, M.D.
Brown University	Cynthia Garcia-Coll, Ph.D.
Columbia University, NYSPI	David Shaffer, M.D.
Columbia University Institute for Juvenile Research, Dept of Psychiatry	Mary McKay, Ph.D.
Columbia University Teachers College, Dept. of Human Development	Jeanne Brooks-Gunn, Ph.D.
Columbia University	Laurence Greenhill, M.D.
Columbia University	Hector Bird, M.D.
Columbia Univeristy	Danny Pines, M.D.
Cornell University Medical College	Beatrix A. Hamburg, M.D.
Duke University	Lenore Behar, M.D.
Duke University	Kenneth A. Dodge, Ph.D.
Duke University	E. Jane Costello, Ph.D.
Hastings Center for Biomedical Ethics	Erik Parens, Ph.D.
Harvard University Mass Gen Hospital	Michael Jellinek, M.D.
Harvard University	Wiliiam Beardslee, M.D.
Iowa State University	Rand Conger, Ph.D.
International Society for Research in Child/ Adolescent Psychopathology	Sir Michael Rutter, Ph.D.
Johns Hopkins School of Public Health	Phil Leaf, Ph.D.
Med Univ of South Carolina Family Services Research Center	Scott Henggeler, Ph.D.
New York University	Harold Kopelwicz, M.D.
Northern Illinois University	Michael Epstein, Ph.D.
Pennsylvania State University	Mark Greenberg, Ph.D.
Rutgers University	Robert Johnson, M.D.
SUNY, Buffalo	William Pelham, Ph.D.
University of California, Berkeley	Stephen P. Hinshaw, Ph.D.
University of California, Davis Nat'l Center on Asian-American Mental Health	Stanley Sue, Ph.D.

University of California, Los Angeles	Howard Adelman, Ph.D.
University of Colorado	Delbert Elliott, Ph.D. (303) 49201266
University of Colorado	David Olds, Ph.D.
University of Illinois, Chicago	Patrick Tolan, Ph.D.
University of Puerto Rico, Medical Sciences Campus	Glorisa Canino, Ph.D.
University of South Florida	Mary Evans,Ph.D.
University of South Florida	Al Duchnowski,Ph.D.
University of South Florida	Krista Kutash, Ph.D.
University of Maryland	Mark Weist, Ph.D.
University of Massachusetts	Thomas Grisso, Ph.D.
University of Michigan, Dept of Health Behavior & Education	Cleopatra Caldwell, Ph.D.
University of Pennsylvania	Ray Lorion, Ph.D.
University of Pennsylvania	John Fantuzzo, Ph.D.
University of Pennsylvania	Margaret Spencer, Ph.D.
University of Pittsburgh, Dept. of Psychology	Danny Shaw, Ph.D.
Vanderbuilt University	Mark Wolraich, M.D.
Yale University Med. School Child Study Center	James Leckman, MD
Yale University	Edward Ziegler, M.D.
Yale University	Alan Kazdin, Ph.D.
Child Abuse and Neglect Int'l Journal	Richard Krugman, M.D.

Family Members, including Youths (28)

Anita B. Shelton

Palma Bucher

Jacki McKinney

Manaja Unjinca Hill

Shannon CrossBear

Sandra Spencer

Angelica Andino

Trina W. Osher

Jane Adams

Gail Daniels

Philipa Hambrick

Donna Davis

Darlyn Johnson

Susan Rogers

Sacred Child Project – North Dakota	Oren Hill
Sacred Child Project – North Dakota	Carmen Bruce
Jefferson County Community Partnership – Alabama	Terrell Williams
Jefferson County Community Partnership – Alabama	Shalanda Smith
Southwest Community Partnership – Michigan	Angelique Harris
Southwest Community Partnership – Michigan	Patricia Harris
	Jill Schalansky
New Mexico Advocates for Children and Families	Mario Benavidez
Children and Families in Common Project: Washington	Minal Kode
Children and Families in Common Project: Washington	Janea Bellows
Children and Families in Common Project: Washington	Rutia Curry
Children and Families in Common Project: Washington	Stephanie Lane

Nebraska Family Central- Nebraska	Logan Stickney
Nebraska Family Central- Nebraska	Kendra Wooden
Nebraska Family Central- Nebraska	Stacy ?

Providers

Mental Health

Boys & Girls Town of Missouri	Vince Hillyer
Guidance Center, Inc.	Susan Ayers, LCSW
George Washington University	Jack Susman, Ph.D.
Kaleidoscope, Inc.	Karl Dennis
Kentucky Cntr for Mental Health Studies Inc	Paul Weaver, Ed.D.
Louis de la Parte Florida Mental Health Institute	Mario Hernandez, Ph.D.
Michigan Assn for Children with Emotional Disorders	Virgil Bernero
MHMRA	Regenia Hicks, Ph.D.
Univ of Maryland, School of Social Work	Walter Harvey
U. Cinncinati, Children's Medical Center	Frank Putnam, M.D.

Primary Care

Children's Hospital of Philadelphia	William Carey, M.D.
Iowa Dept. of Public Health	Edward Schor, M.D.
Kennedy Krieger Institute	Gary Goldstein, M.D. President
South Carolina Children's Hospital of Pediatrics	Ronald T. Brown, Ph.D.
Primary Care Family Therapy Clinics, Inc.	Brenda Reiss-Brennan, A.P.R.N., C.S.

Education

Bermuda Run Educational Center	Jeanne Knieriemen, Director
Cambridge Public Schools	Chris Deyeso
Los Angeles Unified Schools	Marlene Wong
LaGrange (IL) Area Department of Spec. Ed	Lucile Eber, Ed.D.
JFK Medical Center	Gordon Williamson
NEA Health Information Network	Angela M. Oddone, MSW, LCSW Mental Wellness Prog Coord
Stonewall Jackson High School	Katherine Black
South Carolina Research Institute	Bill Brown

UNC-Chapel Hill, Frank Porter Graham Child Development Center	Rune Simeonsson, Ph,D.	
Safe Schools/Healthy Students Initiative	Judy Scales, Project Director	
Safe Schools/Healthy Students Initiative	Cindy Erickson, Project Director	
<u>Juvenile Justice</u> Wrap around Milwaukee	Bruce Kamradt	
Norfolk Consortium	George Pratt, Ph.D.	
San Francisco Public Defenders Office	Patricia Lee, J.D.	
Yale Child Study Center	Steven Marans, Ph.D.	
Howard University	Hope Hill, Ph.D.	
<u>Child Welfare</u> University of Oklahoma HSC	Dolores Subia Bigfoot	
New York University	Hiro Yoshikawa	
University of North Carolina	Rick Barth	
University of Pennsylvania	Carol Wilson Spigner, D. S.W.	
University of Oregon	Hill Walker	
<u>Faith</u>		
Episcopal Diocese of Massachusetts	Tom Shaw, SSJE	
Long Beach Asian Pacific Mental Health Program	Rev. Chhean Kong	
Interfaith Health Program @ Carter Center	Rev. Fred Douglas Smith	
<u>Substance Abuse</u> (2) Office of National Drug Control Policy	Donald Vereen, Jr. MD., MPH	
Chestnut Health Systems	Michael Dennis, Ph.D.	
<u>Other</u>		
Cambridge Health Alliance	Terry Cline, Ph.D.	
(Bev's recommendation)	Barbara Cooke, Ph.D.	
Georgetown University Medical Center	Dr. Joseph Ballanti	
Mohegan Tribe of Indians of Connecticut Mohegan Tribe	Marilynn Malerba	Director of HHS for
Missouri Dept of Mental Health	Roy C. Wilson, MD	

Author	Lawrence Diller, M.D.
University of North Carolina	Dr. Martha Kaufman
Consultant, Child Welfare and Cultural Competency	Vivian Jackson
Philadelphia Department of Health	Estelle Richman
Yale Child Study Center	Jean Adnopos, MPH
We Care	Sandra Spencer
Family Voices PIC Project	Betsy Anderson, Director
King County Mental Health	Charles Huffine, M.D.
Palm Beach County Health Care District	Dr. Seth Bernstein
Institute of Medicine	Michele Kipke, Ph.D.
Western Pennsylvania Caring Foundation Inc.	Charles P.Lavallee, Vice President
Hispanic Committee of Virginia	Karen Wedekindt
Self-Help Program	Janai Lowenstein, M.S.
Lt. Governor, Hawaii	Mezie Hirono
National Center for Education in Maternal and Child Health Georgetown University	Linda Randolph, M.D. MPH

SURGEON GENERAL'S LISTENING SESSION ON CHILDREN'S MENTAL HEALTH JUNE 26TH, 2000

SUMMARY

The Office of the Surgeon General is planning a national conference on children's mental health September 18 – 19, 2000. The purpose of the conference is to engage families, professionals, and scientists in a meaningful dialogue about issues involved in identifying, recognizing, and referring children with mental health problems for appropriate, evidence-based treatments or services. In preparation for this conference, the federal interdepartmental coordinating committee, representing a broad range of children's mental health concerns, solicited input from a broad range of associations, organizations, and individuals on the issues delineated above. This input was obtained by establishing a special web site on the Surgeon General's home page and through direct mailings to over 500 organizations, associations, or persons across the country. We received close to 400 responses.

In order to craft, refine, and further develop the agenda, a listening session with the Surgeon General was held on June 26th, 2000. Approximately 50 persons attended, in addition to numerous federal representatives. The input from this listening session, based on the discussions of five breakout groups, is presented below.

Over-arching themes identified by participants:

There is no mental health equivalent to the federal government's commitment to childhood immunization. Such a commitment is needed in order to reduce stigma, re-direct resources, and re-prioritize children's mental health. Related issues included:

1. Ensuring screening and early identification of children within key service systems.
2. Providing adequate and appropriate education and training to front-line providers, including pediatricians, family physicians, teachers and educators, child care workers, and persons involved in the juvenile justice system.
3. Educating the public about mental health and illness in children.
4. Engaging families in all aspects of service delivery (i.e., identification, assessment, services).
5. Bridging research and clinical practice to ensure the implementation of evidence-based treatments and services.

A fundamental problem identified by participants was the lack of a primary mental health care system for children. The responsibility for children's mental health care is a divided up among many systems such as education, pediatrics, juvenile justice, child welfare/social services, and specialty mental health. These systems lack a financial understructure with which to support the range of services needed by children and families.

Other ingredients identified as key to a mental health care system included:

1. A Developmental approach and ecological model. Identification, assessment, and treatment models should take into account the multiple factors that affect children's development, including ecology/context (i.e., family, neighborhood, school, day care, community influences).
2. Family Engagement. Children rarely have isolated, well-defined problems that do not affect in some way their family members or caretakers. Family members and local community members should be key partners providing input into the planning, design, and review of research, and may provide valuable information regarding recruitment, retention, and cultural appropriateness.
3. Cultural competency/infusion. The issue of cultural competency and infusion needs to be central to the creation of more appropriate services that take into account traditions, beliefs, and value systems, thus enhancing utilization by diverse population.

4. Triage System. A better triage system is needed to ensure that the appropriate level of care can be provided according to evidence-based strategies in a coordinated fashion.
5. Funding. Different points of view were expressed. Some argued that funds existed, but were ineffectively allocated. Others argued that insufficient resources currently exist. Suggestions were made for better regulation at a federal level to oversee and sanction the appropriate use of funds (e.g., EPDST) at the state level, so as to facilitate the identification and treatment of children at an earlier stage, before their illness progress and co-morbid conditions occur. Consensus emerged that a better system is needed to coordinate or share costs, so that the burden is not placed on family. Fiscal mechanisms to provide developmentally informed assessment and service delivery in an integrated way are also needed.

1. What are the key barriers to identifying, recognizing or referring children with mental health needs (e.g., definitional, systems, training, assessment issues, costs, etc.)?

Aside from the above-identified issues, other key barriers identified by participants include:

a. Lack of collaborative models of practice (e.g., school-based mental health system). For example, pediatricians have limited access to appropriate mental health referrals.
b. The over-focus on diagnosis rather than on functional impairments. By focusing on functional impairments rather than psychiatric diagnoses, we may be able to disconnect identification and referral for treatment from the stigma and mystic associated with mental illness.
c. Need for psychometrically sound procedures of child development and functioning that can be applied at key stages of development (e.g., well-baby visits, key school transitions, etc.)
d. Stigma and myths surrounding mental health in children, resulting in denial, fear, ostracization, discrimination, etc. Perhaps the best method to combat stigma is effective treatment.

2. What are the major challenges to using evidence-based strategies to identify and treat children with mental health problems?

a. A major challenge to using evidence-based strategies that was unanimously identified is the difficulty in translating research into practice. Evidence-based treatments are difficult to implement in the real world because of practice differences in existing systems; lack of time and reimbursement; and lack of applicability to heterogeneous populations, with comorbid diagnoses, problems of poverty, cultural and language differences, etc. Expressed concerns include the rigidity of most evidence-based strategies and their failure to adequately take into account individual differences, contextual, and ecological differences.
b. Another issue is availability of funding for research on real world practices, on dissemination and implementations of models that are practical, on reimbursement for new evidence-based strategies, on appropriate and comprehensive evaluations, and on the impact of provider incentives for utilizing evidence-based strategies.
c. A related issue is training and education. Current CME courses are generally deemed ineffective. There is a need to identify and disseminate the evidence-based strategies in ways that will encourage use by practitioners.
d. Suggestions for addressing these issues include the following:
    i. Better understanding of what is in practice in the real world.
    ii. Assess what is realistic within a system to facilitate the implementation of evidence-based strategies.
    iii. Determine the ability of providers and systems to use evidence-based treatment.
    iv. Assess the utility of evidence-based treatment in the real world.
    v. Assess providers' readiness for change.

3. What are the major service obstacles to delivering mental health care to children and families?

In addition to the overarching issues raised previously, specifics related to delivering care include:

a. The lack of coordination between the private and public sectors; between insurance companies and providers; between acute crisis and long-term care providers, between providers in systems (e.g., education, mental health, medical) and among agencies. A more seamless system to facilitate access to mental health care and communication among the different systems is needed.
b. Inadequate or inappropriate services.
    i. Aside from the disparity of services between states, other barriers to access include long application process, insurance obstacles, long waitlists, transportation issues, lack of wrap around services, lack of family involvement, and shortage of competent professionals who can implement evidence-based strategies.
    ii. There are also concerns about the over-utilization of medications as a primary treatment modality to cut cost. This is particularly concerning in light of lack of demonstrated efficacy, as well as long-term safety and effectiveness of psychotropic medications.
    iii. Lack of support for, and hence under-utilization of psychosocial treatments with the child and family by the school, insurance companies, etc.
c. Inappropriate or inadequate diagnostic system. A developmentally sensitive diagnostic classification system that takes into account functional impairment, ecological/contextual issues is needed to adequately address children's mental health needs. Decisions for reimbursement of services are often based on adult models and fail to take into account the complexities of children's developmental stages and the family context.
d. Lack of competently trained professionals.
    i. There is a need for readily available best practices or standard of care guides to facilitate appropriate delivery of evidence-based services.
    ii. Few incentives for providers to use evidence-based strategies (e.g., not reimbursed by insurance or not required by insurance to use such strategies; no oversight agency like the FDA, which regulates pharmacological treatments).

4. What are the key research and service priorities in children's mental health?

Research Priorities include:

a. Treatment efficacy, effectiveness, and implementation of evidence-based practices.
b. Short term vs. long term pharmacological and non-pharmacological treatments; better measures of functional outcomes
c. Cost-impact studies of treatments and services
d. Prevention and resilience:
    i. Applying the evidence base
    ii. Desistance among high risk populations
e. Translational research on practitioner behavior and how to change it: How to influence current practice?
f. Epidemiology (e.g., prevalence data), including young children (0 – 5)
g. Impact of managed care on identification, access, treatment and outcome
h. Other issues: impact of poverty on child development; impact of racism on mental health, adolescent development and transition into adulthood, child neglect, abuse, and domestic violence.

Service Priorities include:

a. Education and training: Connecting evidence-based strategies and practice.
b. Collaboration and integration of services among different agencies:
    i. Matching children to appropriate services based on best practice standards and comprehensive assessment.

ii. Facilitating access of evidence-based services by bridging the gap between research and practice.
iii. Integrating mental health services in the schools and primary care.

c. Family- or community- centered strategies, parent training and education.
d. Prevention: applying the evidence-base.
e. Early intervention (in terms of age as well as early treatment).
f. Increase resources or incentives for provision (e.g., through federal or state regulation, reimbursement, legal action, internalizing costs by making agencies responsible for failures).

Surgeon General's Conference on Children's Mental Health
Tentative Agenda
7/18/00

September 18, 2000

8:00 – 8:15 Welcome
Dr. David Satcher
Surgeon General

8:15 – 10:00
Panel 1: Identifying, recognizing and referring children with mental health needs.

Identification of mental health needs (1 + family member) 20 min

(Content: Broad picture of unmet needs, health disparities. Discrepancy between need and availability of services. Integrate all systems involved (e.g., juvenile system, child welfare). Pros and cons of labeling, diagnosis vs. functional impairments, based on a developmental perspective)

Primary care and identification of mental health needs: (1 + family member) 20 min

Schools and identification of mental health needs (1 + family member) 20 min

Preschool and identification of mental health needs (1 + family member) 20 min

(Content for the above three sections: What is the evidence for MH needs in various systems (Epidemiology)? How are MH needs dealt with? Are primary care and education equipped to identify and screen for MH problem: status of screening tools and their applicability? How are identified children triaged? What is the boundary between MH vs. education vs. primary care? When does it become a mental health issue? Who is responsible for providing services?)

Discussants (3-4) 25 min

10:00 – 10:15 **BREAK**

10:15-12:00
Panel 2: Access, and availability: Delivering mental health services in communities

Access and barriers to care: Issues in health service disparities (1+family member)

(Content: Pathways into, through, and out of services systems. Adequacy or appropriateness of care. Levels of coordination – disconnect between referral and specialty care).

Stigma (1 + family member) 20 min

(Content: Various perspectives on stigma: What creates stigma? How has it changed? How does it affect willingness to access MH services? What is its impact on health providers, services delivered and families?)

Cultural competence and family engagement (1+family member) 20 min

(Content: Cultural attitudes, beliefs and practices and their impact on access and use of MH services. Alternative settings for MH services such as church, community centers, schools, primary care, childcare, home.)

Organization and financing of services (1+family member) 20 min

(Content: Structure of reimbursement systems and impact on access and use of MH services. Public vs. private partnerships. Economics of competition – consumer education (family perspective))

Discussants: (3-4) 25 min

12:00-2:00 **Working lunch and break out discussion groups**

Break out discussion groups (Facilitators and rapporteurs to be identified from the guest list) Suggested groupings: 10 groups of about 30 persons each

Discussion questions:
In process of development

2:00 –4:00 Reports from Break-out groups (led by rapporteurs for each group) 10 minutes each

4:00 - 5:30 General discussion

September 19, 2000

8:00 – 9:45
Panel 3: State of the evidence on treatments and services (with an emphasis on evidence-based interventions that link health, education, and families)

Prevention, Early Intervention and Services (1 + Family member) 20 min

(Content: State of the evidence on effectiveness of these models, including respite care, wrap-around services, etc. Where is the evidence strongest?)

State of the evidence on treatments (1 + Family member) 20 min

(Content: Synthesis of the evidence on behavioral, pharmacological, and combination treatments.)

Fidelity of implementation of the evidence base (1 + family) 20 min

(Content: Key elements in implementing effective services in the community)

Research to Practice Gap: Why the Gap and What to Do (1 + family member) 20 min

(Content: The gap in various settings/systems. What can researchers do? What can providers do? How to improve collaboration/partnership?)

Discussants (3-4) 25 min

9:45 – 10:00 **BREAK**

10:00-12:00 Breakout session: Facilitated as before. (10 groups, 30 per group)

12:00-2:00 Working Lunch and Reports from Breakout group (10 minutes each)

2:00-3:30 General Discussion

3:30 – 5:30 *Final session: Summary of Findings*

The final session will identify key points from the two break out sessions. The major focus would be on achieving agreement from the major professional associations, family groups, and invitees about the respective responsibilities and roles vis-a-vis identifying, recognizing, referring, and treating children with mental health problems, based on the best available evidence. The intent is for the Surgeon General to be able to issue a call to action based on the recommendations that come from this conference and from the FDA and NIMH October conference on medications in preschool children.

Mental Health: A Report of the Surgeon General
Chapter 3: Children and Mental Health
Summary

1. Childhood is characterized by periods of transition and reorganization, making it critical to assess the mental health of children and adolescents in the context of familial, social, and cultural expectations about age-appropriate thoughts, emotions, and behavior.

2. The range of what is considered "normal" is wide; still, children and adolescents can and do develop mental disorders that are more severe than the "ups and downs" in the usual course of development.

3. Approximately one in five children and adolescents experiences the signs and symptoms of a DSM-IV disorder during the course of a year, but only about 5 percent of all children experience what professionals term "extreme functional impairment."

4. Mental disorders and mental health problems appear in families of all social classes and of all backgrounds. No one is immune. Yet there are children who are at greatest risk by virtue of a broad array of factors. These include physical problems; intellectual disabilities (retardation); low birth weight; family history of mental and addictive disorders; multigenerational poverty; and caregiver separation or abuse and neglect.

5. Preventive interventions have been shown to be effective in reducing the impact of risk factors for mental disorders and improving social and emotional development by providing, for example, educational programs for young children, parent-education programs, and nurse home visits.

6. A range of efficacious psychosocial and pharmacologic treatments exists for many mental disorders in children, including attention-deficit/hyperactivity disorder, depression, and the disruptive disorders.

7. Research is under way to demonstrate the effectiveness of most treatments for children in actual practice settings (as opposed to evidence of "efficacy" in controlled research settings), and significant barriers exist to receipt of treatment.

8. Primary care and the schools are major settings for the potential recognition of mental disorders in children and adolescents, yet trained staff are limited, as are options for referral to specialty care.

9. The multiple problems associated with "serious emotional disturbance" in children and adolescents are best addressed with a "systems" approach in which multiple service sectors work in an organized, collaborative way. Research on the effectiveness of systems of care shows positive results for system outcomes and functional outcomes for children; however, the relationship between changes at the system level and clinical outcomes is still unclear.

10. Families have become essential partners in the delivery of mental health services for children and adolescents.

11. Cultural differences exacerbate the general problems of access to appropriate mental health services. Culturally appropriate services have been designed but are not widely available.

USA TODAY

August 8, 2000, Tuesday, FINAL EDITION

SECTION: LIFE; Pg. 10D

LENGTH: 411 words

HEADLINE: Parents prescribe second opinion It's hard to just say no to a system that wants to medicate schoolkids

BYLINE: Karen Thomas

BODY:

Educators and parents of troubled students are going to court to argue whether children need to use drugs such as **Ritalin.**

Administrators in 7-year-old Kyle Carroll's school district in Albany, N.Y., called protective services, alleging child abuse, when Michael and Jill Carroll said they wanted to take their son off **Ritalin** because of side effects (sleeplessness and appetite loss). He began taking the drug after he fell behind in the first grade and started disrupting class.

At a subsequent family court hearing, a psychologist and pediatrician testified that the boy should remain on the drug. The judge in the case, however, told the couple they could get a second opinion.

In another case, Patricia Weathers of Millbrook, N.Y., says she's thankful she got a second opinion before child protective services knocked on their door. "If by chance we did not have that letter from that one psychiatrist, I think back and cringe. (The officer) could've said, 'This kid's gone.' " Officials determined that anonymous allegations of "medical negligence" were "unfounded."

Weathers' son Michael Mozer, now 10, had problems in school from the first grade. He was disruptive, often talking out of turn and inappropriately touching things. Once, he cut another student's smock during art.

Years of drug cocktails, including **Ritalin** and Dexadrine, made Michael withdrawn, his mother says. With the introduction of Paxil, he began to hallucinate. She disagreed when the school-recommended psychiatrist said that if he weren't medicated, the boy would have to be hospitalized. She took him to a new doctor, who also disagreed and, luckily, she says, put it in writing. Michael now attends a private school, where he is taking no medication and is on a special diet.

Experts have studied nutrition and behavior modification, along

with drug therapy, to treat children diagnosed with attention deficit and hyperactivity disorder (ADHD).

Government research released last week from the National Institutes of Health adds to findings that medication improves the abilities of ADHD kids. The new study shows that non-medicated ADHD kids are three times slower at making quick decisions than their non-ADHD counterparts; that slowness vanished with methylphenidate (**Ritalin**). Says lead researcher Arthur Kramer, a psychologist from Illinois: "Kids who are well diagnosed with ADHD can benefit from (drug) treatment."

GRAPHIC: PHOTO, B/W, Will Waldron, AP, for USA TODAY; Drug-free: After a struggle with public school administrators, Patricia and Roman Weathers put 10-year-old Michael Mozer in a private school and on a special diet without medication.

LANGUAGE: ENGLISH

LOAD-DATE: August 08, 2000

USA TODAY

August 8, 2000, Tuesday, FINAL EDITION

SECTION: LIFE; Pg. 1D

LENGTH: 490 words

HEADLINE: Parents pressured to put kids on drugs Courts, schools force **Ritalin** use

BYLINE: Karen Thomas

BODY:

Some public schools are accusing parents of child abuse when they balk at giving their kids drugs such as **Ritalin,** and as judges begin to agree, some parents are medicating their children for fear of having them hauled away by authorities.

It's an emerging twist in the growing debate about diagnosing and medicating children with attention deficit disorder (ADD) and attention deficit and hyperactivity disorder (ADHD):

* An Albany, N.Y., couple put their 7-year-old son back on **Ritalin** after a family court ruled that they must continue medicating him for ADD.

* Child protective services visited another New York couple to check out anonymous allegations of "medical neglect" after they took their son off **Ritalin** and other drugs because of side effects, the couple say.

"This is relatively new, but it's happening," says Maryland psychiatrist Peter Breggin, who is aware of similar cases in Boston. Often, he says, divorced parents disagree on medicating kids, and judges recently have ruled in favor of the parent who wants to medicate.

The Albany case is apparently the first pitting educators against parents that progressed to a judge's ruling.

"This is going to be happening more and more," says psychologist Peter Jensen, who is on the board of Children and Adults With Attention Deficit Disorder, a national parents group that advocates combining drug and behavior treatments.

As many as 3.8 million schoolchildren are diagnosed with ADD/ ADHD, according to the American Academy of Pediatrics. At least 2 million take **Ritalin,** a stimulant, for symptoms such as inattentiveness, impulsivity and sometimes hyperactivity. Many others are treated

with different drugs.

Government research released last week from the National Institutes of Health adds to the many findings that show medication improves the abilities of ADHD children.

The latest study shows that non-medicated ADHD kids are three times slower than their non-ADHD counterparts making quick decisions; the slowness vanished with methylphenidate **(Ritalin)**.

Lead researcher Arthur Kramer, a psychologist from Illinois, says, "Kids who are well-diagnosed with ADHD can benefit from (drug) treatment."

But should parents be forced to put their children on drugs?

"It's becoming increasingly clear that this is a powerful treatment that can be lifesaving for some children," Jensen says. "We as a society do the same thing with parents who don't immunize or get dental care for their kids. We worry, even though the risk is trivial. The risk for severe ADHD going untreated is not trivial."

The long-term effects of children taking stimulants have not been studied. And psychology professor William Frankenberger, who has studied ADD/ADHD at the University of Wisconsin-Eau Claire for more than 20 years, says it's "disturbing to take a decision like that out of parents' hands."

LANGUAGE: ENGLISH

LOAD-DATE: August 08, 2000

FOCUSTM
Search: General News;Ritalin

To narrow this search, please enter a word or phrase:

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Example: **House of Representatives**

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Washington, D.C. 20201
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To:	Heather Howard	**Date:**	09/14/00
Fax #:	(202) 456-2878	**Pages:**	12, including this cover sheet.
Tele #:			
From:	Dr. Beverly Malone		
Subject:	Children's Mental Health Conference		

COMMENTS: _New Agenda

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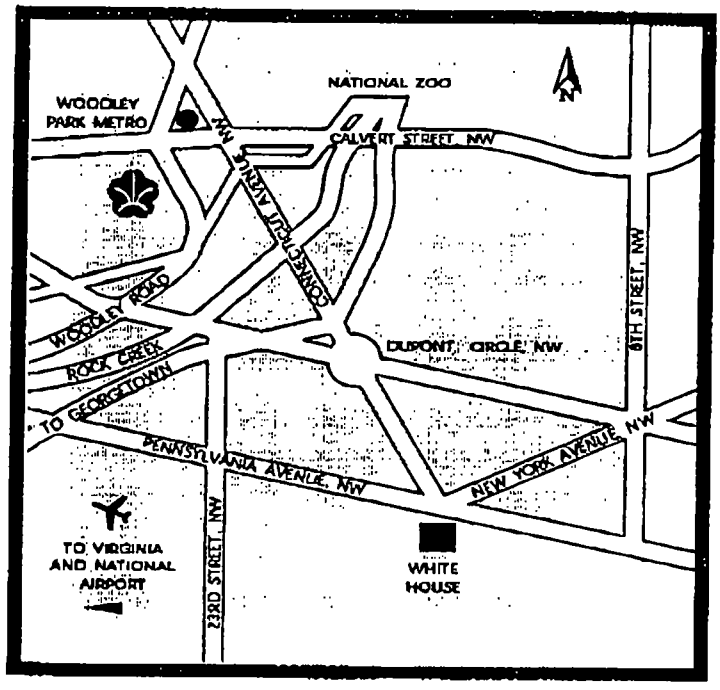

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Follow George Washington Pkwy. northbound to Wash. D.C.; follow past the Pentagon to the Memorial Bridge; While on the Bridge get into right lane and exit at Independence Dr.; follow Independence Dr. back under the Bridge along the Potomac River (this becomes Rock Pkwy.); Get into left lane; Road splits after passing under Bridge, bear left; Exit left at Calvert Street; Turn left off ramp; Hotel is located on the left.

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95 North to 395 North: Take Memorial Bridge exit #8B. Stay in the right lane; continue right off of the bridge onto Rock Creek Parkway. Follow Rock Creek Parkway to the Calvert Street exit. Turn left onto Calvert Street and the Omni Shoreham Hotel is on the left.

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TO THE OMNI SHOREHAM HOTEL FROM PHILADELPHIA

Take I-76 to I-95 South through Pennsylvania, Delaware and Maryland. Take 495 West towards northern Virginia -- Exit #33 – Connecticut Avenue South into Washington, DC. Go approximately four miles and the National Zoo is on the left. Continue another three (3) blocks to Calvert Street. Make a right turn onto Calvert Street. The Omni Shoreham Hotel is on the left.

6/27 FDA

Pediatric advisory subc.

Diane Murphy etc. (301) 827-2350 (301) 594-5400

① FDA having Advisory Cmte mtg Sept. 11 talking about ethical issues re children

Neuropharm div. + NIMH will present & Cmte what we know

- approaches how to study children
- placebo controlled trials in children; also - tell the subc. how they are proposing doing; No science base

addressing

② NIMH/FDA research mtg - Oct 2 + 3 psychopharmacology for young children - Clinical needs & Research opportunities

bringing in author of JAMA article

how do you develop valid diagnosis in young children

how do you test effect in your children

what are we diagnosing in kids?

→ big mtg ← (also people)

how do you look at safety

how do we study w/o harming kids

★ developing the science base necessary to develop the protocols - so basically they are a way from actually developing protocols - they still have to develop the science base

↳ asking for their input

until we have appropriate diagnoses we can't even start trials

we have the most science in field of ADHD - good

let's be responsible we start w/.

Luvox - OCD

Buspirone

2. products used to treat OCD + general anxiety disorder that acts general exclusivity —
are studied down to 6, 8 to 8 years of
will learn from here
will be labeled
kids w/ metabolizing dysfunction + won't
getting therapeutic dose (correct dose —
needed w/ c metabolizing)

NIMH

Multi-site trial — in process of being funded

Surgeon General's Conference on
Children's Mental Health: Developing a National Action Agenda

Working Agenda
8/10/00

September 18, 2000

8:00 – 8:30 Welcome
David Satcher, M.D., Ph.D.
Surgeon General
Steven Hyman, M.D.
Director, National Institute of Mental Health
Bernie Arons, M.D.
Director, Center for Mental Health Services

8:30– 10:30
Panel 1: Identifying, recognizing and referring children with mental health needs.

Chair:, Mary Jane England, M.D., Washington Business Group on Health

Identification of mental health needs 20 + 10 min

(Content: Broad picture of unmet needs, health disparities and policy implications. Discrepancy between need and availability of mental health and substance abuse services. Integrate all systems involved (e.g., juvenile system, child welfare, substance abuse, special health care, etc.). Pros and cons of labeling, diagnosis vs. functional impairments, based on a developmental perspective)
Dan Offord, M.D., McMaster University (to be confirmed)
Senora Simpson, Ph.D., Family Member

(Content for the three sections below: Focus on national data: How are mental health needs identified or recognized in various systems and what are the barriers to recognition? How well do these systems identify and refer children with recognized mental health needs? What linkages do or do not exist among these systems? Speakers will provide national data on identification/recognition/referral within these systems and identify, where appropriate, federal or state policies that address recognition, linkage, and treatment services (e.g., EPDST for primary care, IDEA for education)

Primary care and identification of mental health needs 15 min
Kelly Kelleher, M.D., Western Psychiatric Institute

Schools and identification of mental health needs 15 min
Steve Forness, Ph.D., UCLA

THE WHITE HOUSE

WASHINGTON

September 18, 2000

STATEMENT BY FIRST LADY HILLARY RODHAM CLINTON TO THE SURGEON GENERAL'S CONFERENCE ON CHILDREN'S MENTAL HEALTH: DEVELOPING A NATIONAL ACTION AGENDA

I want to applaud Surgeon General David Satcher for bringing together so many advocates and experts today for the Surgeon General's Conference on Children's Mental Health: Developing a National Action Agenda. The work you are doing today and tomorrow has the potential to bring more health and hope to our nation's children -- and more peace of mind to their parents.

Six months ago at the White House, I joined with Health and Human Services Secretary Donna Shalala, Surgeon General Satcher, National Institute of Mental Health Director Steve Hyman, FDA Commissioner Jane Henney, and Assistant Secretary of Education Judith Heumann to launch an unprecedented public-private effort to improve the diagnosis and treatment of children with emotional and behavioral conditions. We came together to address recent troubling reports about the increasing number of young children taking psychotropic drugs, and to help parents concerned about how to best help treat their children.

According to a report in the Journal of the American Medical Association, the number of preschoolers taking psychotropic drugs increased dramatically from 1991 to 1995. The increase for Ritalin alone was 150 percent, and the use of anti-depressants increased over 200 percent. The number of children under the age of five taking clonidine, which is used to treat insomnia in children with attention deficit disorders, tripled. Unfortunately, many of the drugs being prescribed to our youngest children have never been tested on them. None of them have been tested on children under 6, and many have not been tested on children under 16.

As a parent and longtime children's advocate, these findings concern me a great deal, as they do Federal health officials and countless other experts. But, let me be very clear: Our goal has never been to attack these medicines. They have literally been a Godsend for countless adults and young people with behavioral and emotional problems. We know that when children are left untreated, they may fail to reach their God-given potential later in their lives. That's why these efforts to improve the diagnosis and treatment of children with behavioral and emotional conditions are so important. We want the best information for every parent, every doctor, every teacher -- every single person who cares for our children.

At the White House that day, we met with representatives from many of the groups working on the frontlines on behalf of our children. We talked about what more

we could do to ensure that children with emotional and behavioral problems get the right care at the right time. And we discussed many of the difficult questions, which the participants in this conference will be addressing as they help the Surgeon General develop an action plan for the future.

We asked, for example, how are we diagnosing, treating and caring for children with behavioral and emotional conditions? Do we have the best tools to make the most accurate diagnoses? When it comes to drug treatments for children, why are we seeing such great variations by community and race? And what effects do overuse and underuse of these medications have on our children? We also began to ask, why aren't we doing a better job of combining drugs, when necessary, with family therapy and other behavioral modifications? And what are the potential effects on our very youngest children who have not been tested for these prescription drugs and whose brains are in their most critical stage of development?

At this White House meeting, we announced some immediate steps to ensure that children with behavioral and emotional problems get the care they need. I am pleased that we are already making progress in meeting that goal. We know that more research is necessary to ensure that we make more informed decisions about treatments for our children. To address the gap in knowledge, we announced that NIMH would dedicate $5 million to conduct a landmark study examining ADHD and Ritalin use in preschoolers. This five-year study, which NIMH has already begun funding, will shed much needed light on the safety and effectiveness of Ritalin in young children.

Second, we announced that the FDA would look at some common psychotropic drugs and begin determining what dosage levels are appropriate for very young children. The goal is to put this critical information right on the drug labels. But, these studies will also address the obvious ethical issues that arise when you examine the use of prescription drugs in such a vulnerable group. The FDA's Pediatric Advisory Subcommittee has already begun meeting to discuss these ethical issues, and to develop protocols for making the best diagnosis in young children. In addition, in October, the FDA and NIMH are holding a joint research meeting: "Psychopharmacology for Young Children: Clinical Needs and Research Opportunities."

Third, information about proper diagnosis and treatment of children with mental health problems has not reached many of the people who need it most -- including parents, teachers, school nurses, social workers, pediatricians and family physicians. Therefore, at our White House meeting, NIMH released a new, easy to understand fact sheet to help parents make the right decisions about their children's treatment. The American Academy of Pediatrics announced it would develop new guidelines to treat and diagnose ADHD. Since then, those treatment guidelines have been issued, and they are already giving vital assistance to health professionals everywhere.

Despite the progress already made, we know there are still many questions we must confront. We must ask whether children diagnosed with emotional and behavioral conditions are provided appropriate care in today's health care system. More specifically,

are they receiving the full range of services they require? Are these services being managed appropriately? And does insurance cover the types of services necessary to provide optimal care?

We also should look at the concerns that have been raised by physicians, patient advocates, and other experts about the extraordinary increase in marketing expenditures for a whole range of medications, including Ritalin. We need to determine whether such marketing has encouraged excessive and inappropriate use of pharmaceutical products or has been constructive in making the public more aware of available treatment options. Moreover, we need to determine the implications of the increased use of these medications in very young populations given the lack of knowledge about their long-term effects.

We need to develop long-term strategies for addressing our children's mental health needs, and your work today and tomorrow will play a large role in making that happen. With your input, the Surgeon General will develop recommendations to improve the way we diagnose, treat, and care for children with emotional disorders.

This week's conference is a very important step, but it is certainly not the last step. I look forward to your recommendations and to working with all of you to ensure that young people get the care they need to have the childhoods and futures they deserve.

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HRC STATEMENT FOR SURGEON GENERAL'S CONFERENCE ON CHILDREN'S MENTAL HEALTH

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PostMaster

09/14/2000 07:55:14 PM

Record Type: Record

To: All EOP Users

cc:

Subject: West Wings Tour Cancellation

MEMORANDUM FOR ALL BLUE PASSHOLDERS

FROM: MARK F. LINDSAY
ASSISTANT TO THE PRESIDENT FOR
MANAGEMENT AND ADMINISTRATION

SUBJECT: West Wing Tours

Due to the State Dinner for His Excellency Atal Bihari Vajpayee, Prime Minister of the Republic of India, West Wing tours will be limited to the hours of 8:00 a.m. - 5:00 p.m. on Sunday, September 17, 2000. West Wing tour hours for the remainder of the week are as follows:

Friday, September 15, 2000	8:00 p.m. to 10:00 p.m.
Saturday, September 16, 2000	1:00 p.m. to 10:00 p.m.
Sunday, September 17, 2000	**8:00 a.m. to 5:00 p.m.**
Monday, September 18, 2000	8:00 p.m. to 10:00 p.m.

Please remember that interns and volunteers may not give tours, and permanent blue passholders may escort up to 6 guests at a time.

Call the Staff Tour and Information Line (ext 6-2002) for updates and changes to the West Wing tour schedule.

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. memo	Heather Howard to Chris re: phone number (partial) (1 page)	n.d.	P6/b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Heather Howard (Subject Files)
OA/Box Number: 21197

FOLDER TITLE:
Surgeon General's Conference Ritalin [Folder 2]

2012-0254-S
rc672

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

[00.2]

To: Chris

P6/(b)(6)

From: Heather Howard

P6/(b)(6)

2 pages follow.

Chris - here's a draft of HRC's statement for the SG's Conference. I have already incorporated Melanne's + Laura Schiller's comments.

Most of it is a rehash from the March event - except for the second & last paragraph, which we want you to look at -- we allude to the marketing + HHS10 problem, to lay the predicate in case we do something on this later. Are you comfortable with the way we did it? Call me at home at P6/(b)(6)

Thanks!

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703-527-
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NIMH National Institute of Mental Health

NIMH Research on Treatment for Attention Deficit Hyperactivity Disorder (ADHD): The Multimodal Treatment Study - Questions and Answers

Children with attention deficit hyperactivity disorder (ADHD), the most common of the psychiatric disorders that appear in childhood, are often the subject of great concern on the part of parents and teachers. Children with ADHD are unable to stay focused on a task, cannot sit still, act without thinking, and rarely finish anything. If untreated, the disorder can have long-term effects on a child's ability to make friends or do well at school or in other activities. Over time, children with ADHD may develop depression, lack of self-esteem, and other emotional problems.

Experts estimate that ADHD affects 3 to 5 percent of school-age children and two to three times as many boys as girls. Children with untreated ADHD have higher than normal rates of injury. ADHD frequently co-occurs with other problems, such as depression and anxiety disorders, conduct disorder, drug abuse, or antisocial behavior.

Although ADHD is relatively common, our knowledge of the problem is incomplete. Current ADHD treatment includes a mix of approaches, such as drug therapy, counseling, supportive services in schools and communities, and various combinations of the three. The medical literature offers many studies carried out over brief treatment periods (3 months or less), but a pressing question remains: what is the best kind of help we can offer children with ADHD over a longer term?

To answer this question, NIMH is sponsoring an ongoing, multisite, cooperative agreement treatment study of children with ADHD entitled *The Multimodal Treatment Study of Children with Attention Deficit Hyperactivity Disorder*. The first findings from this study, which were published in December 1999, provide important guidance for physicians and parents of children with ADHD and are discussed below. Ongoing follow-up reports will be published, with an additional 10-15 papers expected to be released in calendar year 2000.

Questions and Answers

Q. What is the Multimodal Treatment Study of Children with ADHD?

A. The Multimodal Treatment Study of Children with ADHD – "MTA" for short – brought together 18 nationally recognized authorities in ADHD at 6 different university medical centers and hospitals to evaluate the leading treatments for ADHD, including various forms of behavior therapy and medications. The study has included nearly 600 elementary school children, ages 7-9, randomly assigned to one of four treatment modes: (1) medication alone; (2) psychosocial/behavioral treatment alone; (3) a combination of both; or (4) routine community care.

Q. Why is this study important?

A. ADHD is a major public health problem of great interest to many parents, teachers, and health care providers. Up-to-date information concerning the long-term safety and comparative effectiveness of its treatments is urgently needed. While previous studies have examined the safety and compared the effectiveness of the two major forms of treatment, medication and behavior therapy, these studies generally have been limited to periods up to 4 months. The MTA study demonstrates for the first time the safety and relative effectiveness of these two treatments (including a behavioral therapy-only group), alone and in combination, for a time period up to 14 months, and compares these treatments to routine community care. The children involved in the study will be tracked into adolescence to document and evaluate long-term outcomes.

Q. What are the major findings of this study so far?

A. The MTA results published in December 1999 indicate that long-term combination treatments as well as medication-management alone are both significantly superior to intensive behavioral treatments and routine community treatments in reducing ADHD symptoms. The study also shows that these differential benefits extend as long as 14 months. In other areas of functioning (specifically anxiety symptoms, academic performance, oppositionality, parent-child relations, and social skills), the combined treatment approach was consistently superior to routine community care, whereas the single treatments (medication-only or behavioral treatment only) were not. In addition to the advantages provided by the combined treatment for several outcomes, this form of treatment allowed children to be successfully treated over the course of the study with somewhat lower doses of medication, compared to the medication-only group. These same findings were replicated across all six research

sites, despite substantial differences among sites in their samples' sociodemographic characteristics. Therefore, the study's overall results appear to be applicable and generalizable to a wide range of children and families in need of treatment services for ADHD.

Q. Given the effectiveness of medication management, what is the role and need for behavioral therapy?

A. As noted in the NIH ADHD Consensus Conference in November 1998, several decades of research have amply demonstrated that behavioral therapies are quite effective. What the MTA study has demonstrated is that on average, carefully monitored medication management with monthly follow-up is more effective than intensive behavioral treatment for ADHD symptoms, for periods lasting as long as 14 months. All children tended to improve over the course of the study, but they differed in the relative amount of improvement, with the carefully done medication management approaches generally showing the greatest improvement. Nonetheless, children's responses varied enormously, and some children clearly did very well in each of the treatment groups. For some outcomes that are important in the daily functioning of these children (e.g., academic performance, familial relations), the combination of behavioral therapy and medication was necessary to produce improvements better than community care. Of note, families and teachers reported somewhat higher levels of consumer satisfaction for those treatments that included the behavioral therapy components. Therefore, medication alone is not necessarily the best treatment for every child, and families often need to pursue other treatments, either alone or in combination with medication.

Q. Which treatment is right for my child?

A. This is a critical question that must be answered by each family in consultation with their health care professional. For children with ADHD, no single treatment is the answer for every child; a number of factors appear to be involved in determining which treatments are best for which children. For example, even if a particular treatment might be effective in a given instance, the child may have unacceptable side effects or other life circumstances that might prevent that particular treatment from being used. Furthermore, findings indicate that children with other accompanying problems, such as co-occurring anxiety or high levels of family stressors, may do best with approaches that combine both treatment components, (i.e., medication management and intensive behavioral therapy). In developing suitable treatments for ADHD, each child's needs, personal and medical history, research findings, and other relevant factors need to be carefully considered.

Q. Why do many social skills improve with medication?

A. This question highlights one of the surprise findings of the study: although it has long been generally assumed that the development of new abilities in children with ADHD (e.g., social skills, enhanced cooperation with parents) often requires the explicit teaching of such skills, the MTA study findings suggest that many children can often acquire these abilities when given the opportunity. Children treated with effective medication management (either alone or in combination with intensive behavioral therapy) manifested substantially greater improvements in social skills and peer relations than children in the community comparison group after 14 months. This important finding indicates that symptoms of ADHD may interfere with their learning of specific social skills. It appears that medication management may benefit many children in areas not previously well known to be salient medication targets, in part by diminishing symptoms that had previously interfered with the child's social development.

Q. Why were the MTA medication treatments more effective than community treatments that also usually included medication?

A. There were substantial differences between the study-provided medication treatments and those provided in the community, differences mostly related to the quality and intensity of the medication management treatment. During the first month of treatment, special care was taken to find an optimal dose of medication for each child receiving the MTA medication treatment. After this period, these children were seen monthly for one-half hour at each visit. During the treatment visits, the MTA prescribing therapist spoke with the parent, met with the child, and sought to determine any concerns that the family might have regarding the medication or the child's ADHD-related difficulties. If the child was experiencing any difficulties, the MTA physician was encouraged to consider adjustments in the child's medication (rather than taking a "wait and see" approach). The goal was always to obtain such substantial benefit that there was "no room for improvement" compared with the functioning of children not suffering from ADHD. Close supervision also fostered early detection and response to any problematic side effects from medication, a process that may have facilitated efforts to help children remain on effective treatment. In addition, the MTA physicians sought input from the teacher on a monthly basis, and used this information to make any necessary adjustments in the child's treatment. While the physicians in the MTA medication-only group did not provide behavioral therapy, they did advise the parents when necessary concerning any problems the child may have been experiencing, and provided reading materials and additional information as

requested. Physicians delivering the MTA medication treatments generally used 3 doses per day and somewhat higher doses of stimulant medications. In comparison, the community-treatment physician generally saw the children face-to-face only 1-2 times per year, and for shorter periods of time each visit. Furthermore, they did not have any interaction with the teachers, and prescribed lower doses and twice-daily stimulant medication.

Q. How were children selected for this study?

A. In all instances, the child's parents contacted the investigators to learn more about the study, after first hearing about it through local pediatricians, other health care providers, elementary school teachers, or radio/newspaper announcements. Children and parents were then carefully interviewed to learn more about the nature of the child's symptoms, and rule out the presence of other conditions or factors that may have given rise to the child's difficulties. In addition, extensive historical information was gathered and diagnostic interviews were conducted to establish whether or not the child exhibited the long-standing pattern of symptoms characteristic of ADHD across home, school, and peer settings. If children met full criteria for ADHD and study entry (and many did not), informed parental consent with child assent and school permission were received; the children and families then were eligible for study entry and randomization. Children who had behavior problems but not ADHD were not eligible for study participation.

Q. Where is this study taking place?

A. Research sites include:

- New York State Psychiatric Institute at Columbia University, New York, N.Y.
- Mount Sinai Medical Center, New York, N.Y.
- Duke University Medical Center, Durham, N.C.
- University of Pittsburgh, Pittsburgh, PA.
- Long Island Jewish Medical Center, New Hyde Park, N.Y.
- Montreal Children's Hospital, Montreal, Canada
- University of California at Berkeley, CA.
- University of California at Irvine, CA.

For More Information on Mental Disorders in Children, Contact:

Office of Communications and Public Liaison, NIMH
Information Resources and Inquiries Branch
6001 Executive Blvd., Room 8184, MSC 9663
Bethesda, MD 20892-9663
Phone: 301-443-4513
TTY: 301-443-8431
FAX: 301-443-4279
Mental Health FAX 4U: 301-443-5158
E-mail: **nimhinfo@nih.gov**
NIMH home page address:
http://www.nimh.nih.gov

March 2000

March 17, 2000

MEETING ON THE SAFE USE OF MEDICATION FOR YOUNG CHILDREN WITH EMOTIONAL AND BEHAVIORAL CONDITIONS

Date: Monday, March 20, 2000
Time: 10:00 AM – 10:45 AM
Location:
From: Ann O'Leary, Heather Howard and Ruby Shamir

I. PURPOSE

To demonstrate your commitment to children's health by gathering health and education experts to discuss the appropriate treatment of young children with emotional and behavioral conditions.

II. BACKGROUND

Overview

This event focuses on the controversy surrounding the recent increase in the prescription of stimulants and antidepressants to preschoolers despite the lack of information about the safety and efficacy of these drugs for young children.

While progress has been made in diagnosing and treating children with emotional and behavioral conditions, justifiable concerns have been raised about the inappropriate over- and under-utilization of medications such as Ritalin, clonidine, and antidepressants in the very young. Just as important, there is a lack of understanding among parents, teachers and health professionals about the best diagnostic, pharmacalogical, and behavioral interventions now available.

Several themes have emerged from our discussions with health professionals: 1) parents need more information on how to deal with children who are experiencing behavior changes – signs to look for, how to get help, when and what medication is appropriate; 2) the importance of proper diagnosis, and the collaboration between parents, educators, and mental health professionals that is necessary for such a diagnosis; 3) when psychotropic drugs may be appropriate, in combination with other therapies, and 4) the importance of careful monitoring and management of treatment.

At the event, along with Secretary Shalala and representatives of parents and a broad range of health professionals, you will announce a public-private effort to develop strategies to ensure that children with emotional and behavioral conditions are appropriately diagnosed, treated, monitored, and managed by qualified professionals.

Policy Deliverables

1. *NIMH Information for Parents*: One major theme of the event will be the importance of giving parents the information they need to help insure their children receive appropriate care. To that end, NIMH has developed an easy to understand Q&A fact sheet on treating children

with mental and behavioral conditions. This fact sheet will be available on the internet, [and the groups participating in the event have agreed to distribute the fact sheet through their members – *will we know if this is the case on Sunday?*].

2. *Announcement of Federal Conference on the Treatment of Children with Behavioral and Mental Disorders*: The Surgeon General will coordinate a conference with HHS, the Department of Education and representatives of the provider, research, consumer advocacy, and education communities. Topics of discussion will include: developing a research strategy to develop interventions that can be used by providers nationwide; how best to ethically determine the efficacy and safety of medications in young children; and strategies to address the difficulty of accurate diagnosis in preschoolers.

3. *NIMH Research*: NIMH will announce that it is dedicating $X in research to determine the efficacy of medications used to treat behavioral and emotional conditions in very young children. This research, conducted in concert with FDA, will assemble the latest information on the use of these drugs, determine safety and efficacy, and identify discrepancies between clinical practice and scientific evidence.

4. *Additional Pediatric Labeling Efforts*: FDA will announce that it will work with its Pediatric Advisory Commission to design research protocols that will be used to develop new pediatric dosage information to be included on the labels of drugs such as methylphenidate (generic name for Ritalin), clonidine, and other drugs commonly used in children. These studies will be designed to address the ethical issues associated with the study of these drugs in this vulnerable population.

5. *Private Sector Efforts*: You will praise private sector efforts to improve diagnosis and treatment protocols for young children under the age of six.

JAMA Report

On February 23, 2000, JAMA published a report, "Trends in the Prescribing of Psychotropic Medications to Preschoolers," which found that the prescription of psychotropic medications for preschoolers increased dramatically between 1991 and 1995. *Attach the abstract?* There were numerous press reports on this issue in response to the study; several are attached.

The studies published in JAMA, reviewing selected provider data, found that:

- The number of children aged two through four taking stimulants such as Ritalin more than doubled. Ninety percent of preschoolers on medication were on Ritalin or a similar stimulant to treat attention deficit disorders, and the number of these children increased 169 percent over the five year period.
- In this five year period, the number of children under the age of five on clonidine, which is used to treat insomnia in children with attention deficit disorders, tripled.
- *Many children are inappropriately treated.* Studies indicate wide geographic variation in the numbers of children receiving psychotropic drugs such as Ritalin. One study indicated that in some suburban areas, as many as 40 percent of children were on Ritalin, as opposed to less than X percent of children in urban areas [*get NIMH cite from Devorah]*. Other research indicates racial variations as well: a study of one Maryland HMO indicated that African-

Americans children were 2.5 times less likely to receive Ritalin as white children. This wide variation in treatment patterns supports the need for more research to determine appropriate treatment protocols for children with behavioral disorders.

- *Failure to treat emotional and behavioral disorders has severe life-long consequences.* Studies suggest that many children with untreated emotional and behavioral disorders fail to reach their full potential. Brain damage causing lifelong pyschological or social damage may stem from an on-going cycle of punishment and ostracism for behaviors that the child cannot control without help. Children with these types of problems are at significantly higher risk for anti-social activities later on than those without behavioral problems. Accurate, early diagnosis, with education, support, and if necessary and appropriate, medication, can overcome many early problems and help prevent long-term negative behavior.
- *More research is necessary to ensure informed treatment decisions.* Many drugs of the being prescribed to very young children have not been tested in children under the age of 16; none have been tested for children under the age of six. More research is necessary to ensure that providers and parents have the information they need, especially information about the impact of medication on brain development, to make appropriate treatment decisions.

In December, the Surgeon General published the first-ever Surgeon General's Report on Mental Health, stemming from the White House Conference on Mental Health led last June by Tipper Gore. Several important messages on children and mental health came out of the conference and subsequent report: 1) children are not just small adults – their brains are very different and are continually developing, and thus what we know about the impact of medication on adults does not necessarily translate to children; 2) there is a lack of training among pediatricians and family practitioners about how to handle mental health issues in children; 3) the stigma of mental illness is often worse for children than adults; and 4) it is important to raise public awareness of the mental health problems children face.

Success of Pediatric Labeling Efforts

In 1997, you led efforts to improve the safety of pediatric drugs, championing the passage of the Better Pharmaceuticals for Children Act, enacted as part of the FDA Modernization Act. The new law provides financial incentives for pharmaceutical companies to conduct studies on the effects of their medications on children. The new financial incentives for companies, as well as new regulatory authority for pediatric labeling, have significantly improved the information available to both parents and physicians about the appropriate use of medications for children. In the 18 months since these initiatives have been implemented, research has been completed on 19 drugs, resulting in new safety information being added to six drugs with changes expected for the other 13. Studies of an additional 125 drugs are already underway. In contrast, in the five years preceding the legislation, only 11 studies to gather additional safety information about drugs already on the market were conducted. Of course, much more still needs to be learned about young children with emotional and behavioral disorders.

III. PARTICIPANTS

Open Press Session
Secretary Shalala

Surgeon General Satcher
NIMH Director Dr. Steve Hyman
FDA Commissioner Dr. Jane Henney

Closed Strategy Session
Participants from Open Press Session plus:
Judith Heumann, Assistant Secretary, Special Education and Rehabilitative Services, Dept of Ed.
MaryLee Allen, Director, Child Welfare & Mental Health Division, Children's Defense Fund
Lanny R. Copeland, MD, Chairman of the Board, American Academy of Family Physicians
Gail Daniels, President, Board of Directors, Federation of Families for Children's Mental Health
Kevin P. Dwyer, MA, NCSP, President, National Association of School Psychologists
Michael M. Faenza, MSSW, President & CEO, National Mental Health Association
Randy A. Fisher, President, School Social Work Association of America
Mary E. Foley, MS, RN, President, American Nurses Association
Gregory A. Humphrey, Special Assistant to the President, American Federation of Teachers
Beth A. Kaplanek, RN, President Elect, Children and Adults with Attention-Deficit/Hyperactivity Disorder
Clarice Kestenbaum, MD, President, American Academy of Child & Adolescent Psychiatry
Ronald F. Levant, Ph.D., Board of Directors, American Psychological Association
Harold James McGrady, Jr., MD, Council for Exceptional Children
Allan Tasman, MD, President, American Psychiatry Association
Jane Tustin, RN, MSN, CSN, President, National Association of School Nurses
Phil Walson, Member, MD, AAP Committee on Drugs, American Academy of Pediatrics

IV. SEQUENCE OF EVENTS

The event will have two parts: closed strategy meeting in the Map Room, and then press announcement in the Roosevelt Room.

9:30- 10:30 am	**STRATEGY MEETING** Map Room
10:00am	**THE FIRST LADY** will arrive in the Map Room
10:02- 10:20am	Each group will have 2 minutes to present there accomplishments
10:20- 10:35am	**THE FIRST LADY** will do a photo receiving line with group leaders.
10:35am	Group leaders will be escorted to the Roosevelt Room
10:37am	**THE FIRST LADY** proceeds to the Roosevelt Room joined by Shalala etc.
10:40- 10:57am	**ANNOUNCEMENTS**

- Secretary Shalala will introduce the issue and you, highlighting your leadership.
- You will speak for approximately five minutes.

10:58am **THE FIRST LADY** departs

V. PRESS PLAN

- Open Press for the opening session, closed for strategy session.

VI. REMARKS

- Provided by Laura Schiller.

ATTACHMENTS

FIRST LADY HILLARY RODHAM CLINTON LAUNCHES NEW PUBLIC-PRIVATE EFFORT TO IMPROVE THE DIAGNOSIS AND TREATMENT OF CHILDREN WITH EMOTIONAL AND BEHAVIORAL CONDITIONS

March 20, 2000

Today, First Lady Hillary Rodham Clinton, together with Secretary Shalala and representatives of parents and a broad range of health professionals, launched an unprecedented public-private effort to ensure that children with emotional and behavioral conditions are appropriately diagnosed, treated, monitored, and managed by qualified health care professionals, parents, and educators. Federal actions she will outline include: (1) the release of a new, easy to understand fact sheet about treatment of children with emotional and behavioral conditions for parents; (2) a new $5 million funding commitment by the National Institute of Mental Health (NIMH) to conduct additional research on the impact of psychotropic medication on children under the age of seven; (3) the initiation of a process at the Food and Drug Administration (FDA) to improve pediatric labeling information for young children; and (4) a national conference on Treatment of Children with Behavioral and Mental Disorders to take place this fall. The First Lady will also highlight actions taken by the private sector to ensure appropriate diagnosis and effective treatment of these children. All of these actions build on the landmark work resulting from the first ever White House Conference on Mental Health and the release of the unprecedented Surgeon General's Report on Mental Health last year, both of which were spearheaded by Tipper Gore, the President's Mental Health Advisor.

INAPPROPRIATE DIAGNOSIS AND TREATMENT OF BEHAVIORAL AND EMOTIONAL CONDITIONS HAVE ADVERSE CONSEQUENCES. While progress has been made in diagnosing and treating these conditions, justifiable concerns have been raised about the inappropriate (both over and under) utilization of medications such as Ritalin, clonidine, and Prozac in very young children. Just as important, there is a lack of understanding amongst parents, teachers, and health professionals about the best diagnostic, pharmacological, and behavioral interventions now available. Recent studies published in the *Journal of the American Medical Association* reviewing selected provider data over a five year period found that:

- **Failure to treat emotional and behavioral disorders can have severe life-long consequences.** Studies suggest that many children with untreated emotional and behavioral conditions fail to reach their full potential. Untreated mental illness has a negative impact on the developing brain, causing lifelong emotional and social damage. Children with these types of problems are at significantly higher risk for anti-social activities later on than those without behavioral problems. It is evident that an accurate early diagnosis, education, support, and medication, if necessary, can overcome many early problems and help prevent long-term negative behavior.

- **The number of preschoolers on anti-depressants increased by over 200 percent.** The number of children on tri-cyclic anti-depressants, often used to control bedwetting, increased 220 percent over five years. Given the difficulty of diagnosing depression in children this young and the relative normalcy of bedwetting in children this young, the increase in the use of this drug in preschoolers is troubling.

- **The number of children under the age of five on clonidine increased exponentially.** The 28-fold increase in children using clonidine, used in children with attention deficit disorders or children exhibiting disruptive behaviors, is notable, as the increase in its use occurred without research ensuring that it is safe and effective. Adverse effects, including rapid or irregular heartbeat and fainting, have been reported in children using the drug with other medications for attention-deficit disorder.

- **The number of children aged two through four taking stimulants such as Ritalin more than doubled.** The vast majority of preschoolers taking stimulants were on Ritalin to treat attention deficit disorders – as many as ninety percent in one study – and the number of these children increased by 150 percent over a five year period. Although there are a disproportionate number of boys taking medication for attention deficit disorders as opposed to girls (a ratio of 4:1), the number of girls being diagnosed and treated with attention deficit disorders increased over this time period; in one study, the proportion of girls taking stimulants increased by 60 percent.

- **Many children are inappropriately diagnosed and treated.** Studies indicate wide geographic and ethnic variation in the numbers of children receiving psychotropic drugs such as Ritalin. In one study, the percentage of children receiving Ritalin was as high as 10 percent – 2 to 3 times as high as the expected rate of attention deficit disorder. The percentage of boys receiving medication for attention deficit disorder in the fifth grade was as high as 20 percent. Other research indicates racial variations as well; a study of one Maryland HMO indicated that African-Americans children were 2.5 times less likely to receive Ritalin as white children. This wide variation in treatment patterns supports the need for more research to determine appropriate treatment protocols for children with emotional and behavioral disorders. Although little is known about the effects of over medication on children, unnecessary use of these medications can have adverse effects on the developing brain and the emotional and social development of young children.

- **More research is necessary to ensure informed treatment decisions.** Many of the drugs being prescribed for very young children have not been tested in children under the age of 16; few have been tested for children under the age of six. More research is necessary to ensure that providers and parents have necessary information, especially about the impact of medication on brain development, to make appropriate treatment decisions.

NEW ACTION TO ENSURE BETTER DIAGNOSIS, TREATMENT, AND MANAGEMENT OF CHILDREN WITH EMOTIONAL AND BEHAVIORAL CONDITIONS. At today's meeting, the First Lady will announce a series of public and private actions designed to address the challenges posed by children with emotional and behavioral conditions. Federal actions she will outline include:

- **Initiation of a process for the development of pediatric labeling information for psychotropic drugs used in young children.** Today, FDA will announce that it will work with its Pediatric Advisory Committee to design research protocols that will be used to develop new pediatric dosage information to be included on the labels of drugs such as methylphenidate, clonidine, and other drugs increasingly used in young children. These studies, which will begin after national research goals have been identified, will be designed to address ethical and scientific issues associated with the studies on this population.

- **Announcement that NIMH will dedicate more than $5 million to research on attention deficit disorder and Ritalin use in preschoolers.** Today, the National Institute of Mental Health announced that it plans to invest more than $5 million in research on the use of medication to treat attention deficit disorder in preschool children. This research will assemble the latest information on the use of these drugs and identify discrepancies between clinical practice and current scientific evidence.

- **New efforts to provide parents with up-to-date information on the appropriate diagnosis and treatment of children with emotional and behavioral conditions.** This week, NIMH will release a new fact sheet to help parents of children with behavioral and emotional conditions understand the treatment options available and guide them in their decision-making process. This fact sheet includes easy to understand information on when to include medication in an overall treatment plan; how to help determine if a child's problems are serious; and when and how to get help. The Department of Education will also release an information kit on ways for teachers and parents of children with attention deficit disorders.

- **A national Conference on the Diagnosis and Treatment of Children with Behavioral and Mental Disorders.** This fall, the Office of the Surgeon General, together with NIMH and FDA, will coordinate a Conference on Treatment of Children with Behavioral and Mental Conditions. This national conference, which will build on the success of the recent White House Conference on Mental Health chaired by Tipper Gore, and the Surgeon General's Report on Mental Health, will include representatives of provider, consumer advocacy, and education communities. Topics of discussion include: developing research on treatments and services that can be used by providers nationwide; how best to determine the efficacy and safety of medications in young children; and ways to address the difficulty of accurate diagnosis in preschoolers. The Surgeon General will also release a report on children's mental health by the end of the year.

NEW PRIVATE SECTOR COMMITMENT TO ENSURING APPROPRIATE DIAGNOSIS OF EMOTIONAL AND BEHAVIORAL CONDITIONS IN YOUNG CHILDREN. Today, the First Lady will praise and highlight the new efforts of the American Academy of Pediatrics (AAP) and the American Academy of Family Physicians (AAFP) to ensure appropriate diagnosis and effective treatment of children with emotional and behavioral conditions. This spring and fall, the AAP will distribute new clinical practice guidelines on the diagnosis and evaluation of children with attention deficit disorders. to every one of their 55,000 members. In addition, as part of their focus on mental health in the year 2000, the AAFP will sponsor education courses nationwide for their over 89,000 members on how to address the problems of young children with emotional and behavioral conditions.

HILLARY ROHDAM CLINTON'S LONGSTANDING COMMITMENT TO CHILDREN. For over 25 years, Hillary Clinton has fought to raise awareness and support policies that protect children. She was a strong advocate for: the passage of the Children's Health Insurance Program, the Family and Medical Leave Act; new regulatory and statutory authority for pediatric labeling; administration efforts to improve child care. The new pediatric labeling regulations and the FDA Modernization Act enacted by the Clinton Administration have improved the information available to both parents and physicians about the appropriate use of medications for children. In the 18 months since these initiatives have been implemented, research has been completed on 19 drugs, resulting in new safety information being added to six drugs with changes expected for the other 13. Studies of an additional 125 drugs are already underway.

June 27, 2000

MEMORANDUM FOR HILLARY RODHAM CLINTON

FROM: HEATHER HOWARD

CC: MELANNE VERVEER
LISSA MUSCATINE
ANN O'LEARY

SUBJECT: UPDATE ON EFFORTS TO IMPROVE THE TREATMENT OF CHILDREN WITH EMOTIONAL AND BEHAVIORAL CONDITIONS

Before your interview with the Medical Editor of CBS, I wanted to briefly update you on what has happened since your event in March announcing new Federal efforts to improve the diagnosis and treatment of children with emotional and behavioral conditions.

- **New guidelines for the diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) from the American Academy of Pediatrics.** At your Roosevelt Room event, you announced that the Academy was developing new guidelines for the diagnosis and treatment of ADHD. In May, the Academy released the new treatment guidelines to their 55,000 members. The new guidelines require that ADHD symptoms be present in two or more of a child's settings, and that the symptoms adversely affect the child's academic or social functioning for at least six months. The new guidelines recommend that the assessment of ADHD include information obtained directly from parents or caregivers, as well as a classroom teacher or other school professional, regarding the core symptoms of ADHD in various settings. They also recommend that evaluation include assessment for co-existing conditions, such as learning and language problems, aggression, disruptive behavior, depression or anxiety. The Academy is currently developing the new ADHD treatment guidelines, which are expected to be released this fall.

- **NIMH research.** NIMH is in the process of funding a $5 million multi-site trial on the use of Ritalin to treat ADHD in preschoolers.

- **FDA efforts.** Due in large part to the attention you have focused on this issue, the FDA is now working to develop the science base necessary to create protocols for developing new labeling information for pediatric dosages. In September, the FDA's Pediatric Advisory Subcommittee will be meeting to discuss the ethical issues surrounding studying children, and in October, the FDA and NIMH are holding a joint meeting entitled "Psychopharmacology for Young Children: Clinical Needs and Research Opportunities."

- **Planning for the Fall Surgeon General's Conference on the Treatment of Children with Behavioral and Mental Disorders**. Planning for the conference, scheduled for September 17th and 18th, 2000, is ongoing. On Monday, June 26, 2000, the Surgeon General held a "listening session," to which he invited 50 groups representing healthcare providers, educators, parents, and consumers. Representatives from NIMH, the FDA, SAMSA, and the Center for Mental Health Services also participated. The meeting, which I attended, solicited input on four key questions:

  - What are the key barriers to identifying, recognizing or referring children with mental health needs (e.g., definitional, systems, training, assessment issues, costs, etc.)?
  - What are the major challenges to using evidence-based strategies to identify and treat children with mental health problems?
  - What are the major service obstacles to delivering mental health care to children and families?
  - What are the key research and service priorities in children's mental health?

  The overarching themes in the comments were:

  - The importance of coordination between the different providers in children's lives, including those in the health care, education, and child care systems.
  - The need for better training for health providers and educators, to help them assess children's behavioral and mental problems.
  - The critical importance of proper assessment, which everyone agreed cannot happen during a ten-minute doctor's visit.
  - The importance of involving families in all aspects of treatment, including diagnoses, service design and delivery.
  - The need for research on the zero to five population.
  - The difficulties in translating research into practice.

  As you mentioned in your speech at the March event, pharmaceutical companies and health insurers need to be included in this discussion. The Surgeon General's office has assured me that they will be included in the fall conference.

Launch of New Public-Private Effort to Improve the Diagnosis and Treatment of Children with Emotional and Behavioral Conditions

Remarks by First Lady Hillary Rodham Clinton
Roosevelt Room
March 20, 2000

Thank you all for joining us here this morning. I want to thank Secretary Shalala for her leadership, and I'm also pleased she refuses to sit still. Because whenever our children's health is at stake, she's out there working very hard to make sure we all pay attention.

Also, I'm pleased to be joined not only by Secretary Shalala, but by Surgeon General David Satcher, and FDA Director Jane Henney, and NMIH Commissioner Dr. Steve Hyman, and Dr. Judith Heumann, and representatives from many of the groups who are on the frontlines working on behalf of all of our children, particularly children with behavioral and emotional challenges.

We just came from a meeting where we talked about what more we can do to ensure that children with emotional and behavioral problems get the diagnosis and treatment they need, and when they need it. Today's meeting and the announcements around it are important steps, but they are certainly not the last step we need to take in ensuring that all of our children get the health and support and treatment that they deserve.

You know, when a child comes to us who is hurt or sick, there is nothing more terrifying for any of us, especially parents, when we don't know how to make it better. If they have a broken arm, we want to fix it; if they have a deadly disease, we want to do everything we possibly can to cure it. And it's no different if the problem they bring to us lies in their head or their heart.

Thanks in large part to the leadership of Tipper Gore, the President's mental health adviser, we've come a long way in our battle to bring mental illness out of the shadows and make sure it is treated just as seriously as physical illness. More and more often, those treatments include drugs, even for young children. That is the issue we're here today to discuss.

As many of you know, the Journal of the American Medical Association recently reported that the number of preschoolers who are taking psychotropic drugs increased dramatically from 1991 to 1995. We know that the increase for Ritalin alone was 150 percent, and the use of anti-depressants increased over 200 percent. Now I am no doctor, as is obvious, but I am a parent and I have been a longtime children's advocate. And these findings concern me. I know they concern Dr. Hyman, Secretary Shalala and countless other experts.

But let me be very clear: We are not here to bash the use of these medications. They have literally been a Godsend for countless adults and young people with behavioral and emotional problems. We know that when children with such problems are left untreated, they may fail to reach their God-given potential later in their lives. That's why we are here. We want

the best information for every parent, every doctor, every teacher—every single person who cares for our children.

But we do have to ask some serious questions about the use of prescription drugs in all children. We have to ask, for example, how are we diagnosing, treating and caring for children with behavioral and emotional conditions? Do we have the best tools to make the most accurate diagnoses? When it comes to drug treatments for children, why are we seeing such great variations by community and race? And what effects do overuse and underuse of these medications have on our children?

We need to ask also, why aren't we doing a better job of combining drugs, when necessary, with family therapy and other behavior modifications? And what about the effects on our very youngest children who haven't been tested for these prescription drugs and whose brains are in their most critical stage of development?

These are tough questions, and none of us have all of the answers. But as we made clear in the meeting this morning, we are building on a record, not starting from scratch. We have already taken critical steps over the past few years to ensure that drugs are being tested and labeled specifically for children. Some of you may remember that was a long, drawn out struggle, that we were finally able to make progress and we were able to make an announcement at the White House last year. In so doing, we have learned that finding the right prescription for a child is not always just a matter of decreasing the dosage.

You know, I think it's important that all of us adults recognize that children are not just miniature adults; that their systems, their developmental needs, are different from that of an adult. We also learned quite a bit from the first ever Surgeon General's report on mental illness, which came out in December. It grew out of the White House Conference on Mental Illness, led by Tipper Gore. It taught us that the stigma of mental illness is worse for children; that too many health care professionals lack training in the area of children's mental, emotional and behavioral needs; and that we have a long way to go to increase awareness about children's mental health.

So clearly, we must do more. We know that the questions being raised are very difficult and they cannot be answered overnight. And they certainly won't be answered by the government, or health care professionals or educators or parents acting alone. Every single person with a stake in our children's health has an important role to play.

So I'm very pleased today to announce some of the immediate steps we are taking to make sure that children with mental illness, with behavioral and emotional problems, get the right care at the right time.

As our meeting made clear, we already know a lot about the proper diagnosis and treatment of emotional and behavioral problems in children. But that critical information has not reached many of the people who need it most—many of the parents, many of the teachers, many of the school nurses, many of the school social workers, many of the family physicians, many of the pediatricians—so there are a few things we are going to try to do to change that.

Today, the NMIH is releasing a new, easy to understand fact sheet that parents can use to make the right decisions about their children's treatment for these conditions. The Education Department will soon release an information kit to help parents and teachers better care for children with ADHD. And I want to thank both the American Academy of Pediatrics and the American Academy of Family Physicians for all they are doing on this issue. This spring and fall, the American Academy of Pediatrics will give all of their 55,000 members up-to-date guidelines for diagnosing and treating children with emotional and behavioral problems. And as part of their yearlong focus on mental health, the American Academy of Family Physicians is sponsoring continuing education courses about these conditions for their 90,000 members.

But now we also have to admit, honestly, that there are some areas where we still just don't know enough, and that's especially true when it comes to giving prescription drugs to our very youngest children. I am pleased that NIMH will dedicate over $5 million to conduct a landmark study examining ADHD and Ritalin use in preschoolers. This study will look at the gap between what we are finding out in the science labs and what is happening in clinical practice, so we can ensure that our children get the care they need. In addition, the FDA will look at some common psychotropic drugs and begin a process to find out what dosage levels are appropriate for very young children. This information will then be included on the labels of these medications, and the studies on them will address the obvious ethical issues that arise when you examine the use of prescription drugs in such a vulnerable group.

Finally, I'm delighted that this fall, the office of the Surgeon General will coordinate a national conference on the treatment of children with behavioral and mental disorders. It will bring together experts from the administration, parents, advocates, educators, researchers, healthcare professionals and consumers. It will look at the challenges we are all still facing in caring for children with mental illnesses. It will help us develop long term strategies that each of us can use to help young people get the childhood and chance in life that we all deserve.

I remember, as we were talking today, that I was fortunate, more than 30 years ago, to work at the Yale Child Study Center, one of the premier research institutions in our country when it comes to treating our young children. And I was exposed to some of the greatest minds and experts in the country about how to treat very young children. And there was nothing more challenging and, in many ways, heartbreaking, than a preschooler with obvious mental, emotional and behavioral problems. That child cannot speak for him or herself. So it's often difficult to find out what kind of conditions in the child's life led to—if there is a cause and effect—the kind of behavior that is being observed. So I know firsthand—from 30 years of work on my own behalf, and watching experts who are really on the frontlines of this—that this is a very big challenge we are taking on today.

But I am also concerned that we are seeing increasing numbers of children who are both being diagnosed with certain disorders and whose behaviors are crying out for helpful intervention. We spoke earlier today in our meeting about the increasing number of very young children in foster care. The fastest growing group of children being put into foster care are children under 5. They come into foster care because of abuse or neglect and they therefore have more than the kinds of problems that one would expect in the population at large. We talked about the increasing numbers of children who are in the juvenile justice and criminal justice

systems. We are not doing what we need to do to help intervene and treat those children, just as we are not providing adequate medical and mental health services in our adult prisons. These are problems that affect all of society, not just the individual with the specific problem or that individual's family or those teachers and others that come into contact with that young person. This has ramifications for all of us.

All we need to do is look back a few weeks and think about the 6-year-old that brought the gun to school to kill the other 6-year-old. That is a problem that did not just occur the morning the child picked that gun up off of the bed in that terrible condition in which he was living. So all of us have a stake in the research, the diagnosis and the treatment. And I would also add that we need some other people at the table, and we're going to try to do that through Dr. Satcher's efforts and the efforts of the associations represented here. We need to be sure that the insurance industry, the HMO industry, the pharmaceutical industry—as well as decision-makers at all levels of government—are also at the table. We do have a lot of information about what works, but we need more. And that's what this meeting and these announcements are about. But we should at least be trying to implement what we do know works while we look for more answers, and follow up on the efforts that will be underway.

You know, when a child is sad or misbehaving, it is never easy for even the most well-intentioned, best-meaning parent to figure out what is happening. Anyone who has ever had a child who is pre-verbal with any kind of illness, or a toddler, or a preschooler, knows how difficult it is. Some of these young people have problems that are symptoms of nothing more than childhood or adolescence. Some of them need a parent to love them, or a person simply to listen to them talk about their pain. And yet some do have severe emotional and mental problems that can be greatly helped by prescription drugs. These children are waiting for our help—every one of them—and today we are taking important steps to provide it.

It is my great hope that this meeting will move us closer to the day that we will be able, number one, to remove the stigma from these problems so that no parent or no community has to wonder whether this is something that should be talked about, or help should be sought for. And number two, that we will treat the problems of the body and the mind the very same.

I hope that all of us will see this as a beginning and that we will be even more committed to doing whatever it takes to make sure that our children get the help, support and love that they need to have.

Thank you all very much.

Launch of New Public-Private Effort to Improve the Diagnosis and Treatment of Children with Emotional and Behavioral Conditions
Remarks by First Lady Hillary Rodham Clinton

Indian Treaty Room
Roosevelt Room
March 20, 2000

Thank you all for joining us here this morning. I want to thank Secretary Shalala for her leadership, and I'm also pleased she refuses to sit still. Because whenever our children's health is at stake, she's out there working very hard to make sure we all pay attention.

Also, I'm pleased to be joined not only by Secretary Shalala, but by Surgeon General David Satcher, and FDA Director Jane Henney, and NMIH Commissioner Dr. Steve Hyman, and Dr. Judith Heumann, and representatives from many of the groups who are on the frontlines working on behalf of all of our children, particularly children with behavioral and emotional challenges.

We just came from a meeting where we talked about what more we can do to ensure that children with emotional and behavioral problems get the diagnosis and treatment they need, and when they need it. Today's meeting and the announcements around it are important steps, but they are certainly not the last step we need to take in ensuring that all of our children get the health and support and treatment that they deserve.

You know, when a child comes to us who is hurt or sick, there is nothing more terrifying for any of us, especially parents, when we don't know how to make it better. If they have a broken arm, we want to fix it; if they have a deadly disease, we want to do everything we possibly can to cure it. And it's no different if the problem they bring to us lies in their head or their heart.

Thanks in large part to the leadership of Tipper Gore, the President's mental health adviser, we've come a long way in our battle to bring mental illness out of the shadows and make sure it is treated just as seriously as physical illness. More and more often, those treatments

include drugs, even for young children. That is the issue we're here today to discuss.

As many of you know, the Journal of the American Medical Association recently reported that the number of preschoolers who are taking psychotropic drugs increased dramatically from 1991 to 1995. We know that the increase for Ritalin alone was 150 percent, and the use of anti-depressants increased over 200 percent. Now I am no doctor, as is obvious, but I am a parent and I have been a longtime children's advocate. And these findings concern me. I know they concern Dr. Hyman, Secretary Shalala and countless other experts.

But let me be very clear: We are not here to bash the use of these medications. They have literally been a Godsend for countless adults and young people with behavioral and emotional problems. We know that when children with such problems are left untreated, they may fail to reach their God-given potential later in their lives. That's why we are here. We want the best information for every parent, every doctor, every teacher—every single person who cares for our children.

But we do have to ask some serious questions about the use of prescription drugs in all children. We have to ask, for example, how are we diagnosing, treating and caring for children with behavioral and emotional conditions? Do we have the best tools to make the most accurate diagnoses? When it comes to drug treatments for children, why are we seeing such great variations by community and race? And what effects do overuse and underuse of these medications have on our children?

We need to ask also, why aren't we doing a better job of combining drugs, when necessary, with family therapy and other behavior modifications? And what about the effects on our very youngest children who haven't been tested for these prescription drugs and whose brains are in their most critical stage of development?

These are tough questions, and none of us have all of the answers. But as we made clear in the meeting this morning, we are building on a record, not starting from scratch. We have already taken critical steps over the past few years to ensure that drugs are being tested and labeled specifically for children. Some of you may remember that was a long, drawn out struggle, that we were finally able to make progress and we were able to make an announcement at the White House last year. In so doing, we have learned that finding the right prescription for a child is not always just a matter of decreasing the dosage.

You know, I think it's important that all of us adults recognize that children are not just miniature adults; that their systems, their developmental needs, are different from that of an adult. We also learned quite a bit from the first ever Surgeon General's report on mental illness, which came out in December. It grew out of the White

House Conference on Mental Illness, led by Tipper Gore. It taught us that the stigma of mental illness is worse for children; that too many health care professionals lack training in the area of children's mental, emotional and behavioral needs; and that we have a long way to go to increase awareness about children's mental health.

So clearly, we must do more. We know that the questions being raised are very difficult and they cannot be answered overnight. And they certainly won't be answered by the government, or health care professionals or educators or parents acting alone. Every single person with a stake in our children's health has an important role to play.

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Thank you all very much.

President and First Lady | Vice President and Mrs. Gore
Record of Progress | The Briefing Room
Gateway to Government | Contacting the White House
White House for Kids | White House History
White House Tours | Help | Text Only

Privacy Statement

Surgeon General's Conference on Children's Mental Health

The Office of the Surgeon General is planning a major national conference in September on Children's Mental Health. The purpose of the conference will be to engage families, professionals, and scientists in a meaningful dialogue about issues involved in identifying, recognizing, and referring children with mental health problems for appropriate, evidence-based treatments or services. Concerns about inappropriate diagnosis—that is, either over- or under-diagnosis—of children's mental health problems and about the availability of evidence-based treatments and services for children and their families has sparked a national dialogue around these issues.

Presenters and participants will represent a broad cross-section of mental health stakeholders, including pediatrics, education, psychology, social work, psychiatry, nursing, and public health. During the conference, break-out sessions will be formed to identify commonalities across the diverse professional, scientific and family perspectives. Points of agreement and recommendations will then be included in a final report on the conference, which will form the basis of a Surgeon General's Call to Action.

The conference is being organized by a Federal interdepartmental coordinating committee representing a broad range of children's mental health issues. The committee has solicited input from interested groups, associations, and individuals (several hundred comments were received through this web site as of June 19), and key issues of concern to families, service providers, and researchers will be included in the conference.

Because of space limitations, participation in the conference will be by invitation only. Additional information about the conference will be available on this web site later in the summer.

Last updated: July 17, 2000 Site suggestions to: SGWebSite@osophs.dhhs.gov

Surgeon General's Conference on *Children's Mental Health: Developing a National Action Agenda*

September 18 – 19, 2000

Regency Ballroom, Omni Shoreham Hotel
Washington, D.C.

Agenda

September 18, 2000

7:00 – 8:00 **Sign-in at West Promenade Registration Desk**
Continental breakfast
Regency Gallery

8:00 – 8:30 **Welcome**
David Satcher, M.D., Ph.D.
Assistant Secretary for Health and Surgeon General
Steven E. Hyman, M.D.
Director, National Institute of Mental Health
Bernard S. Arons, M.D.
Director, Center for Mental Health Services

8:30 – 10:30 **Panel 1: Identifying, recognizing, and referring children with mental health needs**

Chair: Mary Jane England, M.D., Washington Business Group on Health

Identification of mental health needs
David (Dan) R. Offord, M.D., McMaster University
Senora D. Simpson, Ph.D., Family Member

(Content: Prevalence of mental health needs. Broad picture of unmet needs, health disparities and policy implications. Discrepancy between need and availability of mental health and substance abuse services. Integrate all systems involved (e.g., juvenile system, child welfare, substance abuse, special health care, etc.). Pros and cons of labeling, diagnosis vs. functional impairments, based on a developmental perspective.)

Primary care and identification of mental health needs
Kelly J. Kelleher, M.D., M.P.H., University of Pittsburgh

Schools and identification of mental health needs
Steve Forness, Ed.D., University of California, Los Angeles

Preschool and identification of mental health needs
Neal Halfon, M.D., M.P.H., University of California, Los Angeles

Child welfare and identification of mental health needs
John Landsverk, Ph.D., Children's Hospital, San Diego

Juvenile justice and identification of mental health needs
Linda A. Teplin, Ph.D., Northwestern University

(Content for the above five sections: Focus on national data: How are mental health needs identified or recognized in various systems and what are the barriers to recognition? How well do these systems identify and refer children with recognized mental health needs? What linkages do or do not exist among these systems? Speakers will provide national data on identification/ recognition/referral within these systems and identify, where appropriate, federal or state policies that address recognition, linkage, and treatment services (e.g., EPDST for primary care, IDEA for education).)

Discussants
Donna Gore Olsen, Family Member
Glorisa Canino, Ph.D., University of Puerto Rico
Lucille Eber, Ed.D., The Illinois Emotional/Behavioral Disabilities (EBD) Network, Riverside, IL
Velma LaPoint, Ph.D., Howard University

10:30 – 11:00 **Coffee Break**

11:00 – 12:45 **Panel 2: Health service disparities: Access, quality, and diversity**

Chair: Spero M. Manson, Ph.D., University of Colorado

Access, barriers, and quality
David T. Takeuchi, Ph.D., Indiana University
Margarita Alegría, Ph.D., University of Puerto Rico
Kenneth B. Wells, M.D., M.P.H., The RAND Corporation

(Content: Pathways into, through, and out of service systems. Adequacy or appropriateness of care. Impact of stigma, cultural attitudes, beliefs and practices. Availability of services in non-traditional settings (e.g., church, boys and girls clubs) and gate-keeper settings (e.g, schools, primary care, childcare, homes). Problems with coordination and disparities in access or use of services.)

Reaching out to and engaging families
Barbara Friesen, Ph.D., Portland State University
C. Veree' Jenkins, Family Member
Lynn Pedraza, Ed.S., Family Member

(Content: Factors impacting access to mental health care (e.g., stigma, diagnosis, etc.) and availability of appropriate services. How can we better engage families in evidence-based treatments and services?)

Discussants

Laurie Flynn, NAMI (National Alliance for the Mentally Ill)
Carl C. Bell, M.D., Community Mental Health Council, Chicago
Michael M. Faenza, MSSW, National Mental Health Association
Phillipa Hambrick, Family Member

12:45 – 1:00 **Lunch pick-up**
Please pick up your boxed lunch at the back of the Regency Ballroom and proceed to your assigned break out group. Federal participants must show lunch tickets.

1:00 – 3:00 **Working lunch and break out groups**
Group assignments and map for break out group locations are in your folder.

3:00 – 3:15 **Coffee break**

3:15 – 5:45 **Panel 3: State of the evidence on treatments, services, systems of care, and financing**

Chair: Chris Koyanagi, Bazelon Center for Mental Health Law

Prevention, early intervention, and community-based services

Barbara J. Burns, Ph.D., Duke University
Tim Lewis, Ph.D., University of Missouri

(Content: State of the evidence on effectiveness of services for youth with or at risk for persistent or multiple disorders, including respite care, wraparound services, school-based treatments, etc. Where is the evidence strongest? Where is it weakest?)

State of the evidence on treatments for children and the research to practice gap

John Weisz, Ph.D., University of California, Los Angeles
Peter S. Jensen, M.D., Columbia University
Thomas P. Laughren, M.D., Food & Drug Administration
Evelyn P. Green, M.Ed., MS.Ed., Family Member

(Content: Synthesis of the evidence on psychosocial, pharmacological and combination treatments. The gap in various settings/systems. What is known about evidence-based treatments? Why is knowledge not used? How can knowledge be made more relevant? How can practice be changed?)

Systems of care: Financing and organizing service systems
Sherry Glied, Ph.D., Columbia University
Robert M. Friedman, Ph.D., University of South Florida
Angelique Harris, Youth

(Content: Structure of reimbursement systems and impact on access and use of mental health services. Public-private partnerships. Key elements in implementing effective services in the community. Consumer perspective.)

Discussants
Trina W. Osher, M.A., Federation of Families for Children's Mental Health
Jane Knitzer, Ed.D., Columbia University
Mark Greenberg, Ph.D., Pennsylvania State University
Michael L. Dennis, Ph.D., Chestnut Health Systems

5:45 – 6:30 **General discussion**
Facilitated by Kenneth P. Moritsugu, M.D., M.P.H.
Deputy Surgeon General

September 19, 2000

7:30 – 8:00 **Continental breakfast**
Regency Ballroom

8:00 – 12:15 **Break out groups**
Facilitated as before. Please remain in the same 10 break out groups. Group assignments and map for breakout group locations are in your folder.

Coffee is available in the Regency Ballroom throughout the morning.

12:15 – 1:45 **Lunch (on your own)**
Facilitators and Reporters synthesize recommendations from the break out groups.

1:45 – 2:00 **Reconvene in plenary session**
Regency Ballroom

2:00 – 3:00 **Reporters report back to Dr. Satcher and all participants**

3:00 – 4:00 **General discussion**
Facilitated by Beverly L. Malone, Ph.D., R.N., F.A.A.N.
Deputy Assistant Secretary for Health

4:00 – 4:30 **Final wrap-up and summary**
Facilitated by David Satcher, M.D., Ph.D.
Assistant Secretary for Health and Surgeon General

SURGEON GENERAL'S CONFERENCE ON *CHILDREN'S MENTAL HEALTH: DEVELOPING A NATIONAL ACTION AGENDA*

September 18-19, 2000

Sponsored by

Department of Health and Human Services

Office of the Surgeon General, Office of Public Health and Science

National Institute of Mental Health, National Institutes of Health

Center for Mental Health Services, Substance Abuse and Mental Health Services Administration

Assistant Secretary for Planning and Evaluation, Office of the Secretary

Center for Environmental Health, Centers for Disease Control and Prevention

Food and Drug Administration

Maternal and Child Health Bureau, Health Resources and Services Administration

National Institute on Drug Abuse, National Institutes of Health

Department of Education

Office of Special Education Programs, Office of Special Education and Rehabilitative Services

Department of Justice

Office of Juvenile Justice and Delinquency Prevention, Office of Justice Programs

In collaboration with

Office of Safe and Drug-Free Schools, Office of Elementary and Secondary Education, Department of Education

Administration on Children, Youth and Families, Administration for Children and Families, Department of Health and Human Services

Health Care Financing Administration, Department of Health and Human Services

National Institute of Child Health and Human Development, National Institutes of Health, Department of Health and Human Services

Surgeon General's Conference on
Children's Mental Health: Developing a National Action Agenda

September 18 – 19, 2000

MATERIAL FOR BREAK OUT GROUPS

Guidelines for Break Out Groups

This conference is an important step in the process initiated with the release of the first-ever Surgeon General's report on mental health. During this conference, we hope to build upon this report, which included an extensive chapter on children, and the input received during the Surgeon General's Listening Session on Children's Mental Health held earlier this summer. The purpose of the break out groups is to develop consensus recommendations among the 300 conference participants that can be incorporated into a Surgeon General's National Action Agenda. In order to develop these recommendations, please focus on the attached questions during your break out discussion sessions. Facilitators and recorders will help solicit your best ideas. To facilitate this process, here are some guidelines to help provide the input the Surgeon General needs in order to advocate for children's mental health needs.

1. Brief Introduction: Please limit your introductions to name and affiliation.

2. Brief Commentaries: Allow every member of your group time to provide input, but ask each individual to limit each comment to a minute or less.

3. Concrete recommendations: Please make your comments as specific and solution-focused as possible.

4. Prioritize your top 3 to 5 responses to each question: a democratic process is encouraged.

Questions for Break Out Groups

September 18, 2000

BREAK OUT SESSION #1 (2 hours): Identification of ***major opportunities*** for improving the recognition of child and adolescent mental health needs, referral for treatment or services, and access to appropriate care; identification of ***major policies*** aimed at recognition, referral, and access; identification of ***practitioner training needs*** in child and adolescent mental health.

For the following questions, please have your group both ***list and prioritize*** the barriers to or opportunities for improvement. Keep in mind the range of developmental periods and settings in which children's mental health needs may be recognized. Try to limit your major responses to less than 10 per question. This will facilitate the identification of key consensus recommendations across all of the breakout groups for the final session.

1. What are the major barriers to appropriate identification and recognition of children with changing mental health needs (e.g., lack of collaborative models of practice, lack of good assessment tools to measure functioning, availability of trained practitioners, lack of time, etc.)? Please be sure to identify specific barriers in primary care and school settings, but feel free to identify other settings (e.g., juvenile justice, child welfare, etc.) in which you feel barriers to identification and recognition are especially important.

2. What are the major factors that impede referral and access to appropriate treatments or services (e.g., parity, social, economic, training-related)? Again, please identify specific impediments in primary care and schools, but include other systems as appropriate.

3. What are the major policies, programs or practices (at a federal, state, or local level) that offer the opportunity for strengthening recognition of mental health needs or improving access to care (e.g., parity, CHIP, EPSDT, IDEA, SSI, Head Start)?

Questions for Break Out Groups

September 19, 2000

BREAK OUT SESSION #2: (4 hours): Identification of ***major opportunities*** for promoting child and adolescent mental health and using evidence-based treatments and services; identification of ***major barriers*** to using evidence-based treatments and services; development of ***recommendations*** for closing the gap between research, practice, and policy on children's mental health.

For the following questions, please have your group ***list and prioritize*** the opportunities or barriers (as before). Once again, keep in mind developmental issues and range of settings. Finally, and most importantly, please encourage your breakout group to develop ***specific, well-focused recommendations*** to strengthen or improve policies about these mental health issues.

1. What are the major opportunities for promoting child and adolescent mental health and for preventing risks and antecedents associated with mental illness in different delivery systems?

2. What are the barriers to developing and applying a scientifically-grounded evidence base on treatments and services for children and adolescents with mental health needs (e.g., funding, dissemination of the evidence, training/education of providers).

Recommendations for a National Action Agenda

3. For the following please include policies or practices that involve primary care and school settings, but you need not be limited to only those settings. In making your recommendations, please be as specific as possible. Given the importance of ***family engagement, ecological context, and cultural sensitivity,*** what recommendations do you have for strengthening or improving specific federal, state, or local policies and practices to:

   (a) Increase appropriate recognition of mental health problems and referrals?
   (b) Increase access to treatments or services that are developmentally appropriate?
   (c) Support the use of scientifically-grounded preventions, treatments and services for children and adolescents with mental health needs?
   (d) Promote mental health and prevent risks and antecedents of mental illness?
   (e) Monitor and evaluate the above efforts?

4. Is there a recommendation your group would like to make that was not covered by the questions asked?

Policy Brief

Title II of the Social Security Act, **SSI (Supplemental Security Income) Disability Benefits**, includes benefits for children. Supplemental Security Income is based on the following definitions of disability for children:

- requires a child to have a physical or mental condition or conditions that can be medically proven and which result in marked or severe functional limitations,
- requires that the medically proven physical or mental condition or conditions must last or be expected to last 12 months or be expected to result in death, and
- says that a child may not be considered disabled if he or she is working at a job that is considered to be substantial work.

Title XIX of the Social Security Act, **Medicaid**, is a jointly funded, federal-state program that provides health care coverage to low-income individuals and families. Medicaid eligibility is based on family size and family income. Medicaid is the largest program providing medical and health-related services to America's poorest people. Within broad national guidelines provided by the federal government, each of the states:

- establishes its own eligibility standards,
- determines the type, amount, duration, and scope of services,
- sets the rate of payment for services, and
- administers its own program.

Some of the services that children are able to receive from Medicaid include:

- inpatient hospital care, residential treatment centers, or group homes,
- clinic services by a physician or under physician direction,
- prescription drugs,
- rehabilitative services and/or outpatient hospital services,
- targeted case management, and
- when a state has obtained a waiver, home and community based services are available in place of institutional care.
- **EPSDT (Early and Periodic Screening, Diagnosis, and Treatment)** is the child health component of the Medicaid program. Under EPSDT:
  - states must screen all eligible children, diagnose any conditions found through the screen and then furnish appropriate medically necessary treatment to correct or ameliorate defects, physical and mental, covered by screening services, and
  - an eligible child is entitled to any medically necessary services permitted by the Federal Program even if the service is not included in that particular state's Medicaid plan where the child resides.

Title XXI of the Social Security Act, **CHIP (State Children's Health Insurance Program)**, is designed to provide health care for children who come from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. Under CHIP, the state can chose to provide child health care assistance to low-income, uninsured children through:.

- a separate, private insurance program,
- a Medicaid expansion, or
- a combination of these two approaches.

CHIP targets low-income children and in most states defines them as under 19 and living in families with incomes at or below the poverty line. Children eligible for Medicaid must be enrolled in Medicaid and are not eligible for CHIP. Also, to be eligible for CHIP, children cannot be covered by other group health insurance. If a state chooses to expand Medicaid eligibility for its CHIP program, the children who qualify under CHIP are entitled to EPSDT. If a state chooses to develop a separate private insurance program, it must include the same benefits as the State Employee Program or have an equivalent actuarial value. Mental health and substance abuse benefits under the private insurance option must be equivalent to at least 75% of the actuarial value in the state employment plan.

In administering Part B of the **Individuals with Disabilities Education Act (IDEA)**, the Office of Special Education Programs, U.S. Department of Education, helps states carry out their responsibility to provide all children with disabilities (age 3-21 years) a free appropriate public education that emphasizes special education and related

services designed to meet their unique needs and prepare them for employment and independent living. Children with emotional disturbance may be eligible for special education and related services under IDEA. Additionally, some children with attention deficit hyperactivity disorder may receive services, if identified as eligible under one of the 13 specific IDEA categories of disability. Eligibility is determined by a multi-disciplinary team of qualified school professionals and parents, based on a full and individual evaluation of the child. In addition to special education delivered in the least restrictive environment, eligible children may also receive related services required to assist them benefit from special education. Examples of these services include:

- speech-language pathology and audiology services,
- psychological services,
- physical and occupational therapy,
- recreation, including therapeutic recreation,
- counseling services, including rehabilitation counseling,
- social work services in schools, and
- parent counseling and training.

Each public school child who receives special education and related services under IDEA must have an individualized education program (IEP) that details the child's goals, needed special education and services and where they will be provided, and other information. For a child whose behavior impedes his/her learning or that of others, the IEP team should consider positive behavioral interventions, strategies, and supports to address that behavior. The IDEA also provides for functional behavior assessments and development of behavioral intervention plans for students who present challenging and disruptive behaviors.

Head Start is a federal pre-school program designed to provide educational, health, nutritional, and social services, primarily in a classroom setting, to help low-income children begin school ready to learn. Head Start legislation requires that at least 90 percent of these children come from families with incomes at or below the poverty line; at least 10 percent of the enrollment slots in each local program must be available to children with disabilities. Head Start's goals include:

- developing social and learning skills, including social-emotional development,
- improving health and nutrition, and
- strengthening families' ability to provide nurturing environments through parental involvement and social services.

References

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http://www.hcfa.gov/init/children.htm
Health Resources and Services Administration (HRSA)
http://www.bphc.hrsa.gov and http://www.hrsa.dhhs.gov/childhealth
Maternal and Child Health Bureau
http://www.mchb.hrsa.gov/index.html
Child Care Bureau
http://www.acf.dhhs.gov/programs/ccb
Insure Kids Now
http://www.insurekidsnow.gov/ and National toll free number: 1-877-Kids-Now
Child Welfare League of America
http://www.cwla.org/health/healthfact.html
Office of Special Education Programs (OSEP)
http://www.ed.gov/offices/OSERS/OSEP
OSEP Technical Assistance Center on Positive Behavior Interventions and Supports
http://www.pbis.org
Center for Effective Collaboration and Practice
http://cecp.air.org/cecp.html
National Center on Education, Disability, and Juvenile Justice
http://www.edjj.org
Office of Safe and Drug-Free Schools
http://www.ed.gov/offices/OESE/SDFS

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FIRST LADY HILLARY RODHAM CLINTON SUBMITS STATEMENT ON PRESCRIPTION OF PSYCHOTROPIC DRUGS TO CHILDREN

WASHINGTON, D.C.--First Lady Hillary Rodham Clinton submitted a statement today to the Surgeon General's Conference on Children's Mental Health: Developing a National Action Agenda, being held Sept. 18 and 19 in Washington, D.C. In her ~~testimony~~ statement, the First Lady applauded the Surgeon General for convening ~~scientists, health care professionals and other~~ experts to discuss this important issue. She also noted the progress made in improving the diagnosis and treatment of children with emotional and behavioral conditions.

Mrs. Clinton has long been concerned about this subject and hosted a meeting at the White House last March with Secretary Shalala, parent groups and health professionals to discuss strategies to address the inappropriate utilization of psychotropic drugs on children. At that meeting, the First Lady launched an unprecedented public-private effort to ensure that these children are appropriately diagnosed, treated, monitored, and managed by qualified health care professionals, parents, and educators.

For a copy of Mrs. Clinton's testimony, please contact the First Lady's press office at 202-456-2960.

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